DOCUMENT RESUME

ED 295 368 EC 202 804

TITLE Early Intervention Project. Summary Report, Narrative Report and Supplemental Report.

INSTITUTION Maine Interdepartmental Coordinating Committee for Preschool Handicapped Children.; Maine State Dept. of Mental Health and Mental Retardation, Augusta.; Mid-Maine Medical Center, Waterville.

SPONS AGENCY Office of Special Education (ED), Washington, D.C. Handicapped Children's Early Education Branch.
PUB DATE Sep 87
GRANT G008400798
NOTE 78p.
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS *Agency Cooperation; Clinical Diagnosis; Community Health Services; Cooperative Planning; Coordination; *Delivery Systems; Demonstration Programs; *Disabilities; Handicap Identification; *High Risk Persons; Home Visits; Infants; *Interdisciplinary Approach; Intervention; Prevention; Young Children
IDENTIFIERS *Early Intervention

ABSTRACT

The objectives and activities of a 3-year preventive intervention program are described. The project's goal was to demonstrate a comprehensive, coordinated interagency model of preventive intervention for birth to 3-year-old handicapped or at-risk infants and young children. Following an in-hospital screening process of infants delivered at Mid-Maine Medical Center, home visits were made to confirm or negate any suspected risks or handicaps. Identified infants and their families residing in the four-town project area were then referred to the project's interdisciplinary Service Assessment Team for development of a case plan and delivery of services. The report focuses on difficulties in the design and conduct of the project in relation to such issues as interagency collaboration and communication, parental acceptance of project services, hospital screening, prenatal assessment, home visits, and the Service Assessment Team referral process. Among conclusions reached were that any philosophical issues involved in determining which discipline(s) should be involved in the home visit component of the assessment process should be resolved, and that the participating hospital must have full involvement in planning and must endorse the project fully, prior to its beginning. (JW)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED295368

SUMMARY REPORT

EARLY INTERVENTION PROJECT

A Handicapped Children's Early Education Project
of the U. S. Department of Education

conducted under the auspices of the

Maine
Interdepartmental Coordinating Committee for Preschool Handicapped Children

in conjunction with the

Department of Mental Health and Mental Retardation
(Augusta, Maine)

and the

Mid-Maine Medical Center
(Waterville, Maine)

July 1, 1984 - September 30, 1987
(Grant No. 008400798, Project No. 024BH50008)

Dedicated to

EDMUND N. ERVIN, M.D.

without whose continual and consistent support
the project would not have been possible.

EC 208804

BEST COPY AVAILABLE

CONTENTS

Background

Statewide 3-to-5 System	1
Zero-to-Three Committee	1
Pilot Programs	2
0-to-3 vs. 3-to-5	2
Demonstration Project	2

"Preventive Intervention Program" Expectations

Structure	3
Assessment	3
Service	3
Project Evaluation	4

Realities

Structure	4
Assessment	6
Service	7
Project Evaluation	7

What Was Learned -

- For future projects	9
- Of current value	10

Appendix

Available Materials	12

Letters from Participants

Janie Pinette, Parent Contact Facilitator
Rona Rosenthal, Children's Developmental Project (2)
Debbie Schooley, Caseworker, Department of Human Services
Jeannie Rough, Assessment Coordinator
Lou Parnell, Service Coordinator
Sandra Niles, Public Health Nurse
Rita Currie, Diocesean Supervisor of Home Care Services
Joyce Hubbard, Public Health Nurse Supervisor
Edmund Ervin, M.D., Mid-Maine Medical Center

SUMMARY REPORT

Background

Since 1977, the three departments of Maine state government having the greatest involvement in child and family services - the Department of Human Services (DHS), the Department of Mental Health and Mental Retardation (DMHMR), and the Department of Educational and Cultural Services (DECS) - have been linked by statute in the coordination of services to preschool handicapped children. (Those three departments, joined by the Department of Corrections, now constitute an "Interdepartmental Council" and its range of coordinated activities encompasses a wide spectrum of program areas, impacting children ages 0-to-20 and their families statewide.)

Statewide 3-to-5 System

The organizational grouping of the three departments created by the legislature for this purpose also includes (by statute) parents of handicapped children and representatives of public and private service providing agencies. This group is officially titled the Interdepartmental Coordinating Committee for Preschool Handicapped Children; more commonly (but less euphoniously) referred to as "the ICCPHC" (pronounced "Ick-Pick")! The ICCPHC's initial priority was to coordinate and develop services for handicapped 3-to-5 year old children, identified in accordance with the various categorical definitions of the state's special education regulations. Beginning with three county-wide "coordination sites" and a modest state appropriation to support "preschool coordinators" and a program of screening and assessment, the effort grew so that by 1983 each of Maine's sixteen counties were represented by a Preschool Coordination Program. Governance of each of these is provided by a "Local Coordinating Committee" whose membership reflects the composition of the ICCPHC - regional representatives of state agencies, service providers and parents of handicapped children. Each of the sixteen programs receives a basic state grant channeled through the Division of Special Education (DECS); is eligible for federal preschool handicapped funding in its various manifestations; and may also apply for related dollars available from such agencies as the Division of Maternal and Child Health (DHS); the state's Developmental Disabilities Planning and Advisory Council; the Bureau of Social Services (DHS); and the Bureau of Children with Special Needs (DMHMR). Staff of the Preschool Coordination Programs also may apply for competitive federal grants. Each of the sixteen programs functions with relative independence, under general policies, standards and guidelines developed by the ICCPHC.

Zero-to-Three Committee

In 1982-83, a number of members of the ICCPHC, and others interested, began a voluntary effort to develop guidelines for extending screening, assessment and early intervention services to the 0-to-3 population. Some of the impetus for this effort came from a presentation by Dr. Stanley Greenspan (then conducting an extensive intramural research effort for the National Institute of Mental Health) on the concept and practice of "preventive intervention" for

"at risk" infants and their families. Some impetus came from the fact that Maine's rate of neo-natal survival is among the highest in the nation, but after hospital discharge appropriate contact and services become hard to maintain, and contact may be lost until the child enters nursery school or kindergarten. Some of the impetus came from the commitment in the "state plan" for special education to provide services to children "ages 0-to-20," although the date for this accomplishment had to keep being revised forward.

Pilot Programs

Having developed some basic principles, policies and guidelines, the group approached two of the sixteen Preschool Coordination Programs (the "Special Needs Preschool Program," in Machias, Maine, and the "Opportunities Program," in Norway, Maine) and offered some limited funding in support of a 0-to-3 "pilot" effort. In brief, each site obtained the full-time services of a community health nurse, identified as an "Assessment Coordinator," and diverted some of the activity of the existing Preschool Program Coordinator to a 0-to-3 "Service Coordinator" role. A "working group," or steering committee, of local persons with primary responsibilities for service provision for infants and their families roughly paralleled the functions of the Local Coordinating Committee.

0-to-3 vs. 3-to-5

The following major differences between the statewide 3-to-5 coordination effort and the two 0-to-3 pilot programs were either planned or accepted at the outset, or became more clearly defined as activities were developed:

- the 3-to-5 effort focused on categorical handicaps as defined in the state's special education regulations; the 0-to-3 effort included three categories of "at risk" situations, only some of which could be equated with categorical handicaps.

- the 3-to-5 effort focused primarily on the individual child as the "client" or recipient of services; in working with a 0-to-3 population, the focus needed to be on the infant-and-family as a single unit.

- the primary care providers for the 0-to-3 population included many individuals - primarily from health and medical professions - who were normally not so involved in services to 3-to-5 year olds.

- screening services for 3-to-5 year olds were normally organized around community social service agencies, day care providers, or public school districts; 0-to-3 screening and assessment activities required very close relationships with community hospitals.

Demonstration Project

In early 1984, the Zero-to-Three Committee (which had become a recognized subcommittee of the ICCPHC) decided to prepare an

application to the Handicapped Children's Early Education Program (HCEEP) office in the U. S. Department of Education for a three-year demonstration "Preventive Intervention Program." (Note: The program soon became know as the "Early Intervention Program," or "EIP.") The Maine Department of Mental Health and Mental Retardation (Bureau of Children with Special Needs) was identified as the grant applicant, although it was agreed that the conduct of the activity would be overseen by the ICCPHC through the Zero-to-Three Committee (ZTC). The committee hoped to build on and expand the efforts begun in Machias and Norway through the development of a third program, and to monitor and coordinate all three programs simultaneously.

"Preventive Intervention Program" Expectations

Structure

The application for the Preventive Intervention Program described the Zero-to-Three Committee's expectations.

> "This project will demonstrate a comprehensive, coordinated interagency model of preventive intervention for birth-to-three year old handicapped or at risk infants and children and their families for replication throughout the State of Maine."

To accomplish this, it was determined that the Program Director's position would be donated by the Bureau of Children with Special Needs on a 75%-time basis. A full-time Assessment Coordinator and a full-time Service Coordinator would be hired, supported by a full-time Secretary. The project would be based in one of Maine's community hospitals or medical centers, to be identified if and after the grant application were approved. Membership on Assessment and Service Coordination Teams would be composed of currently-involved agency and community representatives volunteering their time to the project. Grant funds would be budgeted for consultants and training in infant development, family intervention and evaluation (as well as office equipment and some travel expenditures), and some limited purchase of direct services that might be needed but unavailable.

Assessment

The Assessment activity was projected as consisting of an in-hospital screening of all live births followed by a home visit soon after hospital discharge. Specific Assessment instruments and procedures would be developed by project staff, "host hospital" representatives, and Public Health Nursing representatives.

Service

Those infants-and-families determined as being able to benefit from intervention services, based on the Assessment activity, and falling within a defined project population (see the following paragraph on evaluation) would be refered to the Service Coordination Team, which would jointly develop a service plan, assign a case manager, and monitor progress and outcomes.

Project Evaluation

Evaluation of the "demonstration" aspects of the project (to be assisted by staff of the Early Intervention Research Institute of Utah State University) would be through the identification of two populations of infants-and-families. After completion of the "Assessment" portion of the project, random choice would determine which infants-and-families would be referred to the "Service Coordination Team" for collaborative planning and delivery of appropriate services, and which would be referred through existing procedures to existing community agencies, if services were needed. Both populations would be followed during the course of the project, and evaluated in a number of areas. The expectation was that infants-and-families receiving coordinated services would score higher in these areas that those receiving "non-Team" or "normal" services. Evaluation instruments and procedures - like those of Assessment - would be developed by project staff and consultants, working with interested persons from the project site; the general areas proposed for evaluation included Infant/Child Development, Infant/Child - Family Interaction, Family Functioning and Contacts/Relationships with Service Providing Agencies. It was also planned to demonstrate the cost effectiveness of coordinated service delivery.

Realities

Structure

The grant application was submitted in January, 1984 with the expectation that (if approved) award notification would be received around June, 1984 and the start-date would be October 1st. This would have provided the estimated three months necessary (July - September, 1984) to "work the grant through" state Budget and Personnel Department procedures, recruit and hire staff, and identify a "host hospital" project site.

Initial award notification was received in June, 1984, but the applicant was informed that the grant budget period would begin July 1st (rather than October 1st). The actual process necessary to "work the grant through" state procedures took six months (rather than the estimated three) so no staff actually started work until January, 1985.

The planned 75%-time donation of the Project Director's time was encumbered by an unexpected increase in his state-assigned duties and responsibilities. This placed a great additional load on the Service Coordinator, by requiring her to serve as a de facto administrator at the project site, resulting in a corresponding decrease of the time she could expend in promoting interagency, multidisciplinary coordination. It is of great credit to this individual (Helen D. Parnell) that the entire project did not have to be scrapped as the result of this single factor.

The Assessment Coordinator hired was a Public Health Nurse (Jeanne Rough) with many years experience in Maine and in the

geographic area of the project. The job description required a pediatric nursing background; the recruitment of a local nurse with public health experience proved to be an unexpected benefit, not only in communications and relationships with hospital nursing staff but also in the implementation of the home visit portion of the Assessment component. Already-assigned area Public Health Nurses ended up being responsible for the home visits, and it is doubtful that coordinating these activities would have been possible for some one not already "one of them."

The position of secretary quickly evolved into a more complex position. The individual hired (Diane Gilbert) became invaluable in collecting and tabulating the results of the in-hospital assessments and home visits, in addition to performing the routine office procedures of the project. In addition, she handled unexpected components of the project (such as the annual, Christmas-time "Giving Tree" sponsored by Waterville area merchants). Her position was upgraded to that of a Casework Aide midway through the project, and she functioned in this capacity as much as she did as a secretary.

The selection of the "host hospital" became rushed as a result of the unexpected "early start" of the grant year. Additionally, it was pretty completely mismanaged by the Zero-to-Three Committee. Naively expecting that the opportunity for participation in the project would be received with open arms by both medical and administrative representatives of community hospitals alike, an invitational meeting was held, involving some dozen hospitals. Negative responses expressed at this meeting ranged from accusations that the ZTC was essentially proposing "experimentation on human subjects" (due to the Evaluation design), coming from medical personnel, to bitter diatribes against Maine's new Hospital Cost Containment Commission (which allegedly prohibited acceptance of demonstration grants), coming from hospital administrators.

The ultimate - though delayed - invitation (from Mid-Maine Medical Center, in Waterville, Maine) and continual support of the project during its existence were both due primarily to the influence of one of Maine's senior pediatricians (Dr. Edmund N. Ervin) who has long demonstrated his concern for and interest in the practice of early intervention. Dr. Ervin also served as chairperson of the "Working Group" throughout the life of the project.

Community service providers - already overworked and underpaid - did perform heroically as "volunteer" members of the various committees and teams. It takes a "leap of faith" for some one who is perennially behind in his/her primary responsibilities (despite best efforts and 60-hour weeks) to accept the argument that attending one or two additional "team" meetings each month will actually improve productivity and morale and decrease fatigue and discouragement. Project staff saw such leaps rewarded in these ways many times, yet were unable to come up with any "short-cut" to the individual's process of realization!

Training supported by the grant was delivered, was successful in increasing knowledge and changing attitudes, and was warmly received and acknowledged by hospital staff and community providers alike. Many people contributed their talents to these activities - some as paid consultants, others as volunteers, still others in the normal course of their duties. Undoubtedly the highpoint of the training and consultation activities was a full-day workshop by Dr. T. Berry Brazelton and a team of his associates from Boston's Children's Hospital. The joint sponsorship of this activity by the project and the hospital did as much for acceptance of the project as the tremendous demonstrations, lectures and small group discussions did for the knowledge base of individual participants.

Assessment

In-hospital screening of infants and infant-parent interaction was never as fully accomplished as had been desired. Handicaps or risks associated with "Biological" or "Established" criteria were - as expected - identified as the result of routine medical and nursing practices, common to all hospitals. "Environmental" criteria were, however, another matter. Some of the impediments to their routine inclusion in hospital procedures were: the greater difficulty of definition (e.g. many criteria - such as the youthfulness of a teen-age mother - merely indicated a "possibility" of a problem, rather than a definable condition); the fact that they lay outside more traditional nursing practice and experience and were harder to recognize (e.g. concerns about mother-infant bonding); their greater social sensitivity (e.g. inquiring of an unwed mother about the intentions of an infant's father); and the fact that - demonstrably - the project had no wealth of additional resources with which to meet the multigenerational "environmental" needs of low-income, poorly educated, often abused and neglected mothers (so what was the use of identifying these needs?)

A related time-consuming problem was settling on an appropriate "information and consent" form for parents to sign, it finally having been established by the hospital's legal advisors that the screening process required informed consent to protect the institution from possible liability litigation. Other problems (that probably could have been forecast by someone with more experience within hospital settings) included never being fully clear on the relationship and respective authority of the various nursing staffs (Obstetrical, Pediatric, and Nursery) or, for that matter, ever learning who "spoke for" the hospital - the Administrator, the Chief Medical Officer, the Chief of Pediatrics, the Director of Nursing, the Corporation Counsel, the President of the Board, etc. All of these had something to say about the project at one time or another, and some at many times! Compared to these problems, the issues of accessing three shifts of nurses - plus those that only worked weekends or in an "on call" status - and orientation/training problems caused by continual, normal staff turnover, were almost insignificant!

The home visit component of the Assessment activity was less troublesome, except for scheduling and record-keeping. Area Public

Health Nurses already visited "high risk" infants on the basis of routine medical referrals from the hospital. Increasing the population of infants to be visited to all live births (in the four communities identified for project activities within the hospital's total catchment area) presented the PHNs with a workload problem, but not with any philosophical problems or problems related to insufficient training or experience.

As an offset to the workload issue, the Public Health Nurses found that being able to routinely make visits to homes of some healthy and risk-free infants, in functional families, gave them renewed professional energy. Too, there were a significant number of cases in which the home visit became the only way that severe environmental risks to healthy development could be identified. In this light, we found PHNs actively hoping that the more complexly disadvantaged families in their case load would fall into the "Team" population through the random selection process, and so benefit from the Service Coordination Team approach. (This coordinating team became know as the "Service Assessment Team" early in the project. The erstwhile Assessment Coordination Team dissolved once the hospital screening and home visit protocols had been agreed upon.)

Service

As noted earlier, community agency support of the Service Assessment Team was high and consistent, once the necessary "leap of faith" was made. Procedural issues (size of team, use of a "core" group vs. the full Team; frequency of meetings; scheduled vs. on-call meetings; benefits and/or necessity of active parental participation in Team meetings; selection and assignment of case managers; duration of monitoring; frequency of routine reporting of cases back to the Team; etc.) all had to be hammered out and occasionally revised.

The majority of Team members seemed positive about their experiences as Team members, and there were enough occasions of duplication of services being avoided or previously unidentified service possibilities being located to encourage occasionally flagging energies or spirits. Occasional training provided to all team members (both substantive and process-oriented) assisted in the development of "Team identity" and informal cross-training occured all the time, as representatives of one agency learned things they'd never known about another. All Team members, at one time or another - or repetitively - expressed the wish that more resources could have been obtained for the purchase of direct services, as opposed to "case finding" and "coordination" activities.

Project Evaluation
(by Vaughn Hardesty, Evaluation Consultant)

As a result of a number of factors and circumstances, there were not a sufficient number of families in the standard and intervention groups to allow for a meaningful statistical analysis. It was

necessary to make changes, therefore, in the evaluation design of the Early Intervention Program.

The factors and circumstances that necessitated the evaluatation changes were multiple and varied, and involved several aspects of the project. The delayed start-up of the project was, perhaps, the single most significant factor. This was the result of unanticipated delays in the selection of an appropriate site, delays in the hiring of personnel, and the time necessary to train, integrate and coordinate the project and support personnel. Another factor that played a role in reducing the size of our sample was what might be called a "difficulty with the concept" of prevention. When professionals are involved, and frequently overwhelmed, with families and children who are exhibiting problems, it was often difficult to think about prevention and families who <u>might</u> exhibit problems in the future. Likewise, it was difficult to enlist the cooperation of some families who were seen as being at-risk but who did not perceive themselves as having problems. Too, families who became involved in the project were multi-problem families, suffering extreme stress, and many had priorities that did not include evaluation.

In order to maximize the gathering of useful information and continue to attempt to document the usefulness of early intervention coupled with coordinated service planning and delivery, the following changes were made in the evaluation activities of the EIP. In addition to offering stipends to families who participated in the evaluation process. beginning in October, 1986 families were no longer randomly assigned to standard vs. "Team" groups, but were all identified as members of the intervention population. This was done until December, 1986. Families continued to be identified and served after this date, but time remaining in the project's three year period did not permit their periodic, subsequent evaluation.

Again, because of limited numbers and time in the project, no children were assessed with child development measures. Family measures, including the Parent Stress Inventory, were administered and case reports were developed, describing in detail the intervention process, services received and benefits to children and families. Commentaries documenting the benefits and problems encountered were also elicited from individuals and agencies involved in the EIP.

Through December, 1986 fifty-three families had been randomly assigned to either the standard group (S=22) or intervention ("Team") group (S=31). Of these, nine (29%) intervention families and four (18%) standard families were evaluated. The staff diligently tried to get more families in for evaluation, but to no avail. Many had moved from the project area, while others simply refused to come in. In addition, some of the families had refused to participate in the project after the Assessment phase; others simply did not show up for Evaluation purposes even after consenting. On the positive side, a number of the intervention families had obtained employment, and could not get time off from work to be evaluated! It must, of course, be remembered that these families were generally highly stressed, and difficult to maintain contact with for any reason.

With so few formal evaluations, no formal analysis could be performed. However, all of the intervention families rated the Early Intervention Project as being "quite helpful" or "extremely helpful." In addition, all of these families received a number of state and community services. While most undoubtedly would have received some basic services even if they had been members of the standard population, many of the families reported being helped by the project's delivery of counseling, day care, parent support and educational services. The intervention families received more services than the standard families and tended to rate "significant others" and support groups as being more helpful, than did standard families. In addition, six of the nine intervention families obtained Life Stress scores within normal limits on Abidin's Parenting Stress Index (PSI).

Given all the other difficulties described above, it is not surprising that the cost effectiveness of coordinated service delivery was never determined. However, the project did develop rough estimates of the cost per hospital of the Assessment activity (as implemented) and the cost per family of a "typical" preventive intervention, for presentation to legislative committees and others.

What Was Learned -

- For future projects

1. Allow six months prior to the start-up date to recruit and employ staff through state procedures, or DON'T START! The "budget clock" started running July 1, 1984. Staff reported to work January 21, 1985. The first Service Assessment Team meeting was held in November, 1985. Since enthusiasm and support for the project began to decline dramatically five to six months prior to the functional end of its third year, i.e. in January-February, 1987, when it became definite that continued state funding was not going to be provided, the "effective functioning life" of the project was no more than sixteen months, from November, 1985 to February, 1987. (A three month extension, July-September, 1987, was approved for the completion of some previously initiated training and information collecting activities.)

2. Write any funding proposal with full involvement of intended site personnel. The potential lost energy and disappointment (if your proposal isn't funded) is far less damaging than the lost time involved in trying to identify a site and bring it up to speed with the budget clock running!

3. If you're venturing into a foreign land (as a hospital is to a social service administrator) be sure you're accompanied by a native guide who speaks the language well!

4. Define clear-cut and simple lines of authority and responsibility. The EIP's arrangement of a state agency being the grant recipient, with management overseen by the Zero-to-Three Committee of the Interdepartmental Coordinating Committee for

Preschool Handicapped Children, while a local "Working Group" had other - poorly defined - responsibilities, was completely unmanageable!

5. A project's sponsorship and provision of training, consultations and educational programs to project participants is an extremely worthwhile enterprise, both as a way of increasing their knowledge base and as a way of building acceptance and improving morale.

6. Development of objective methods of "scientific" evaluation will undoubtedly take three times as long and be ten times as difficult as you expect.

- Of current value

1. As a result of experiences related to the in-hospital screening component of the Assessment activity, special workshops were conducted statewide by the Division of Public Health Nursing (DHS) on newborn screening. Increased emphasis was placed on the early identification of possible problems in socio-emotional interaction and development.

2. Through efforts at integrating the in-hospital screening and home visit components of the Assessment activity, the forms used by Public Health Nurses to receive and document maternal and newborn referrals was modified to include pre-natal risk factors. Additionally, specific Public Health Nurses in all regions of the state have been assigned a "hospital liason" role with every hospital and medical center, to improve communications and simplify the referral process for both "medically high risk" and "environmentally at risk" infants.

3. Based on the positive aspects and results of "universal home visits" as practiced by the EIP (i.e. of all newborns, rather than just those identified as "medically high risk") the Division of Public Health Nursing (DHS) has adopted this practice as a statewide program goal.

4. Much of Maine's population is scattered and geographically isolated. Public transportation systems only exist in a few of the larger cities. Community Action Program-sponsored "Demand-Response" transportation services are financially limited. Social service reimbursement for transportation has specific eligibility requirements. The EIP activity identified a high proportion of at-risk families with no transportation resources - the father hitch-hiking to work and the mother and any children left completely immobile. As a result of documenting these needs, regional service agencies formed a task force that is still working to amplify and respond to these transportation needs.

5. Coordinated planning by service providers does work. Though the project cannot take total credit in this area, renewed interagency coordination at the local level can be observed throughout Maine. In regional CASSP activities (Children and Adolescent Service System Program, an initiative of the National Institute of Mental Health, for severely emotionally disturbed children), in beginning efforts to

develop Medicaid-reimburseable Case Management activities, and in Maine's response to the 1986 Education of the Handicapped Act amendments (P.L. 99-457), more groups of service providing agencies - both public and private - are coming together and beginning to meet and collaborate regularly.

6. Finally, it is significant to note that Maine's current responses to the challenges and opportunities of Public Law 99-457 are in keeping with the state's accumulated experiences over the past 10 years, including the Zero-to-Three Committee's activities and priorities. The Interdepartmental Coordinating Committee for Preschool Handicapped Children (ICCPHC) has been designated as the "lead agency;" the state plans to integrate optional 0-to-3 services with mandated 3-to-5 services into a "seamless whole" program; and the state is commited to including "at risk" infants and children in its definitions of those elegible for services, together with those who are categorically handicapped. As a result, the Zero-to-Three Committee accepted with equanimity its recent dissolution and the incorporation of its members into other ICCPHC subcommittees and work groups.

January 31, 1988

Edward C. Hinckley
Bureau of Children with
Special Needs (DMHMR)
State House Station # 40
Augusta, Maine 04333

* * *

Other Materials Available

Narrative Report with Case Examples (26 pages; includes definitions of three categories of risk; by Lou Parnell, Service Coordinator, and Tracy Haller, Cooperating Service Coordinator) Attached

Maine Zero-to-Three Assessment Study: Summary Report (35 pages; includes project descriptions of the EIP and the Machias and Norway pilot programs; by Susan Koen, Managing Director, MATRICES Consultants, Inc.)

Zero-to-Three Policy Manaul (10 pages; working draft of preliminary principles and policies for 0-to-3 intervention programs, developed by the multidisciplinary, interdepartmental Zero-to-Three Committee)

Division of Public Health Nursing Screening Tool and Guidelines (6 pages)

Cost Estimates: Assessment (Hospital Screening and Home Visit) and Intervention Components (5 pages; compiled by Project Administrator for purposes of legislative presentation)

Narrative Reports of Pilot Site (Machias and Norway) Experiences (20 pages) Attached

(Single copies of above materials available by request to: Edward C. Hinckley, Field Operations Manager, at the above address.)

Dear Tracy,

The "team process", for me, has been a real growth experience, as well as a benefit to the "health care" process in the community, in my opinion. The multidisciplinary system works, - in spite of the lack of resources (i.e. Mental health, substance abuse professionals)!

Better networking resulted in the process - and unmet needs hopefully will be identified.

Hopefully certain agencies + individuals involved will continue to carry over this "approach" whenever possible, in dealing with clients, ect. Hopefully, present resources will be called upon, as I was for team approach - situations.

"Tracy", it's been wonderful working with you in the relatively short time you've had with EH - and I'll be seeing you at PEDS meetings in the meantime.

Sincerely yours,

Gladys Pigeatte

Mental Health Technician

mid-maine
medical
center
WATERVILLE MAINE (MMC)

SETON UNIT - CHASE AVENUE
PHONE 872-4305

Children's
Developmental
Project

EDMUND ERVIN M D PROJECT DIRECTOR
RONA ROSENTHAL PROJECT CO-ORDINATOR

March 20, 1987

Early Intervention Project
Attention: Ms. Tracy Haller
18 Silver Street
Waterville, ME. 04901

Dear Ms. Haller,

The most significant benefits of the Early Intervention Project were the establishment of screening for all newborns in the nursery and the opportunity for the family to have a visit by a public health nurse at home.

Membership on the Service Assessment Team was an excellent opportunity for professional networking and coordination of services for families with multiple needs. However, the effectiveness of the team was limited by the experimental model. Many families who could have benefited by coordination by the team were not eligible because they fell in the "standard" group. Many "team" families had services well in place and did not need the team. The team was most helpful to families with multiple environmental problems.

Sincerely,

Rona Rosenthal

Rona Rosenthal, Coordinator
Children's Developmental Project

mid-maine
medical
center
WATERVILLE MAINE 04901

SETON UNIT - CHASE AVENUE
PHONE: 872-4305

Children's
Developmental
Project

EDMUND ERVIN, M.D. PROJECT DIRECTOR
RONA ROSENTHAL PROJECT CO-ORDINATOR

May 6, 1987

Ms. Tracy Haller
EIP
18 Silver Street
Waterville, ME. 04901

Dear Tracy,

The Early Intervention Project (EIP) in Waterville was successful in training the hospital nurses to assess all newborns and identify those with established, biological or environmental risk. Enrollment in the project entitled every family to a visit by a public health nurse which was valuable in picking up families with risk factors which might not have been picked up at birth. Therefore, we were able to offer help and early intervention for families at risk for environmental reasons.

The research and evaluation component of the project was not successful due to problems with the model and lack of sufficient numbers of families.

The role of the working committee was never clarified, but the networking that resulted from participation on the committee was extremely valuable.

I hope that this information is helpful to you as you proceed with the evaluation and final report.

Sincerely,

Rona Rosenthal

Rona Rosenthal, Coordinator
Children's Developmental Project

John R. McKernan, Jr.
Governor

Rollin Ives
Commissioner

STATE OF MAINE
DEPARTMENT OF HUMAN SERVICES
AUGUSTA, MAINE 04333

July 22, 1987

Ms. Debra Nugent-Johnston
Bureau of Children With Speical Needs
Region 3 - AMHI Complex
State House Station # 60
Augusta, Maine 04333

Dear Debbie:

This letter is in response to Tracy Holler's request for feedback regarding the effectiveness of the early intervention project. Since it is my understanding Tracy has already left I am forwarding my letter to you. I would like to comment on the project's effectiveness, both as a member of the working committee and former medical center staff member. My comments reflect my personal thoughts as a member of the working committee.

In retrospect, I feel this project has had some very positive benefits at both the macro and the micro level. The project has helped to heighten the awareness of the nursing and medical staff of the medical center to assessment and early intervention issues. I would hope this "awareness" has also extended into the larger community.

One of the major benefits of the project model has been the normalization of the community health nurse visit post discharge. Prior to the project, offering the services of public health nursing to clients only occurred when there was a documented need. This frequently translated to the family, unfortunately, as "the hospital staff feels that we have a problem and we're not coping with it well." This is especially true of high environmental risk families who often are wary of professionals to begin with. The offering of the home visit to every mother has helped to remove that stigma and make this service truly welcome and supportive to many families who might otherwise refuse.

As I look back on the three years of the project, I feel there were many aspects of the model and its implementation that hindered the effectiveness of the project.

I do not feel that in the planning stages of the model there was a clear sense of what was available or needed for this population. I feel that the model did not take the existing medical center and community systems into account. Already established roles within these existing systems were not well incorporated into the design. Much of the assessment coordinators role, for example, was duplicative of what the hospital nursing staff, the hospital social worker, and the public health nurses were already doing.

In addition, it was not clarified initially how the project would relate to the larger medical center. There appeared to be an assumption made in the beginning of the project that the staff would be considered part of the medical center staff. This attempt to have the project be part of the medical center while in actuality being a separate agency housed within the facility was confusing and frustrating from a systems point of view for those of us that had day to day contact with the project and had to work out issues of confidentiality and other clients' rights issues.

As we struggled with these issues it was never clear who had the authority to clarify and resolve these types of problems. There were no direct lines of authority apparent for project staff. The working committees authority was not clearly defined. It was my understanding the committee was conceived and established to direct the work of the project. In reality, the committee appeared to serve more as advisory than directive. In addition, with the added problems of the lack of social work administrative director for the majority of the project's duration and with turnovers in nursing administrators during this same period, these issues, unfortunately, did not begin to get resolved until the project was near completion.

I would recommend that future projects include community participation in planning, and planned strategies to negotiate and integrate services into the established community service system. In addition, lines of authority and relationships among systems need to be clearly defined. These kinds of efforts hopefully, would help facilitate the "ownership" and support of the community of the model and minimize duplicative efforts.

In spite of these problem areas, I feel that the project was a very worthwhile and useful endeavor. I have enjoyed being a member of the working committee very much. This experience has helped me to learn and grow both professionally and personally. Participation in the project has helped to strengthen my commitment to early intervention.

Sincerely

Debbie Schooley

Debbie Schooley, LCSW

DS/bm

150 Capitol Street, Station 11

" EIP "
EARLY INTERVENTION PROJECT
BIRTH THROUGH TWO

18 Silver Street
Waterville, ME 04901
(207) 872-5343

I was the Assessment Coordinator for the Early Intervention Project and now I am wearing two hats as a Public Health Nurse, back to my old job and as the liason for MMMC-Seton Unit for the OB Section.

The Public Health Nurses go way back and I go back over 20 years having been involved in the Early Intervention concept. We always felt that if we got in there early enough, we were able to do some good in helping the parents with their new borns. We always felt that the optomum life out comes for children are facilitated by knowlegable care givers who are psychologically and emotionally available to them. When parents are effective copers they not only provide a more facilitated environment for their children but they also gain more satisfaction from parenting and family life. All family members influence the child's well being and in turn are affected by the child's presence in the family. Early Intervention provides support to families in stressful situations such as pregnancy and birth.

In the organization of the Early Intervention Project, we were able to put some parimeters around getting things done. Actually, the primary point of all of this is we were able to get into the hospital, talk with all of the mothers that gave birth and offer them a visit by the nurse in their community. This enabled the nurse in the area, the Public Health Nurse primarily, to see well babies and well families prior to this, we were seeing "high risk infants and their families." It was quite different and it was a great time, actually, going into a family that is considered in tact and your able to do a great deal of teaching and intervention. Simply because we are working with well babies and well parents and they in turn were ready to be taught intervention and without the project, I think, we still would be working toward the intervention part instead of the prevention part. In talking with the other Public Health Nurses, they have really enjoyed this type of visit. It has really helped them out alot. Being a Public Health Nurse, I have always been active in the early intervention concept. Because of our committment to the well being of families, we were able to strengthen the hospital in the community coordinations to the projects with the infants and their families and were able to strengthen the health component of the entire 0 to 5 age group.

Getting into the disciplinary relm, talking about the service Assessment Team and the working committee, I thought that we were able to contribute a great deal in this area and we were able to define nursing and what it can offer. I believe through the project that the public health nurses role was defined so people could understand exactly what she does. Nursing deals with the human response to the real or potential health problem. I also believe through the SAT's we were able to coordinate efforts and not duplicate services. Many times prior to the SAT's inception a nurse, Child Development Worker, Protective Worker, Homemakers, a whole ram of professionals, were seeing the family and literally almost stepping on each others toes and not knowing which hand was doing what; but through the SAT we were able to define our roles, cut down on the number of visits, each discipline, and coordinate the services. I just hate seeing the SAT go by the way side cause I do feel it contributed a great deal to the health care aspect and it must of to the family. At least the family knew who everyone was and wasn't confused when Sally entered and thought she was the nurse, and it was Peggy Sue.

The Working Committee was also made up of different disciplines and they are, hopefully, our governing board which really never got a chance, I believe, to govern. Decisions were made and they kind of rubber stamped them, which was too bad because as a working committee they could of been strong enough to carry it but weren't given that opportunity. It seems that we built this project, we bought the horse and then got the barn instead of the other way around.

Personally I have gained quite a bit by being part of this project. Through education and through everyday working in the project, I have gained alot and a greater insite into the families. Between Dr. Brazelton and Michael Trout and numerous other people, they have given me so much more to work with enabling me to be a better effector with my families. I definetely appreciate the opportunity of being part of the project and sadness comes in that as it was, it will no longer be, but I know I will keep the concept always in my heart and will work with it and use it everyday. There has been numerous cases not only on my caseload but on every other public health nurse's caseload where we refer to a family and they were "not a high risk family." They have had no risk factors in the environmental, the biological, or the established catagories. They seem to be an intact family and I can site on occasions where I have gone in and seen everything looking great and ready to leave and the mother says "oh by the way," and by the way, was alot of problems, a great deal of problems. I don't think the average couple realizes how stressful having a new born enter their life can be. Alot think that the new born will bring things together and in fact without a strong union in that family, the new born can really split them apart.

I thank you for this opportunity!

Jeannie Rough

" EIP "
EARLY INTERVENTION PROJECT
BIRTH THROUGH TWO

18 Silver Street
Waterville, ME 04901
(207) 872-5343

Key Points about the Project: On a positive note I would say that there are several good things that came out of the project.

The hospital level is of much stronger awareness of the environmental risk catagory that is being utilized in the screening now. I believe that through the offering of the home visits to all Moms we clearly introduced prevention keys that have not been in existence before. Hopefully these pieces will stay.

In thinking about the Service Assessment Team one of the definete pluses about the team was that the net working among the service providers was at a much higher level than it had ever been in the community before. Those families that we did work with, we were able to trim back over lapping services and provide a more expedient efficient service delivery system. Some of the snags as I saw them were that we needed to have a stronger footing with the hospital in the beginning and I think, over time, that would have occurred even with the project as it was. It got off to a slow start because there was alot of confusion about what the project was trying to accomplish even though there was a strong buying from the community members, there was alot of confusion. I would recommend for anyone replicating this project that they have a type structure regarding the administrative flow and that they have a clear understanding and acceptance from the hospital before getting it.

In looking at the SAT, the one down fall was that the funling into the SAT's were slowly through the nurses, a more efficient way of doing it perhaps would be to open that up to any service provider to bring any family with whom they were working with that had a child 0 to 3 to the team. There are alot of ways to handle the team. Each particular agency would need to decide whether they wanted stationary meetings or meetings that were called when there was a child to review. What makes sense for their local area, but I think in general the concept of a Multi Disciplinary Team is a very very sound one. I'm not sure how the report will be included or if it will be included in the final report but I think that there are pieces of that there was very very important. Those pieces that are dealt with float from 0 to 5 and dealt with the structure and community understanding.

John R. McKernan, Jr.
Governor

Rollin Ives
Commissioner

STATE OF MAINE
DEPARTMENT OF HUMAN SERVICES
AUGUSTA, MAINE

ADDRESS REPLY TO

Sandra Niles, R.N. PHN II
Divison of Public Health Nursing
Region 3A
Capitol Shopping Center
Western Avenue
Augusta, ME 04333
Tel: 289-3436

April 23, 1987

Tracy Haller, Service Coordinator
Early Intervention Project
18 Silver Street
Waterville, ME 04901

Dear Ms. Haller:

First my apologies for not responding to your request sooner.

Serving on the Service Assessment Team was very beneficial to me. It provided me with new knowledge of resources and support systems.

The idea of a team concept is excellent. However, I felt that at times the interval for assistance was too lengthy and the Public Health Nurse had already provided the services needed.

Good Luck on your new adventure.

Sincerely,

Sandra Niles RN PHN II

Sandra Niles R.N. PHN II
Divison of Public Health Nursing

SN/sll

Diocesan Human Relations Services, Inc.

HOME CARE SERVICES
P.O. Box 59
224 Main Street - Waterville, Maine 04901
873-1146

Area Offices
Augusta
Bath
Rockland
Skowhegan
Waterville

April 23, 1987

Tracy Haller, Service Coordinator
Early Intervention Project
18 Silver Street
Waterville, ME. 04901

Dear Ms. Haller;

The Early Intervention Project reached numerous at risk families. Services offered by Agencies involved were varied and pertinent to help needed. The intent of the project was excellent. The problem was lack of cooperation and motivation from clients. This problem will need to be worked through.

Sincerely,

Rita Currie

Rita Currie
Assoc. Supervisor

John R. McKernan, Jr.
Governor

Rollin Ives
Commissioner

STATE OF MAINE
DEPARTMENT OF HUMAN SERVICES
AUGUSTA, MAINE

ADDRESS REPLY TO

Mrs. Joyce K. Hubbard, R.N.,Supervisor
Div. of Public Health Nursing
Region 3A
Capitol Shopping Center
Western Avenue
Augusta,ME 04333
Tel: 289-3436

June 10, 1987

Ms Tracy Haller
EIP Service Co-ordinator
18 Silver Street
Waterville,ME 04901

Dear Tracy:

You've asked for a short summary of each person's impression of the Early Intervention Project, and I for one, would find it much easier if you had asked for a five or six page essay. I have been a member of the Working Committee and have been even more closely involved with the project, as Public Health Nursing Supervisor, with a direct link through Jeanne Rough, a public health nurse who served as assessment co-ordinator.

First of all, I want to say I feel prevention is the key to a healthier, more full life style for many of our children, but it is not spectacular, and so often does not get the funding when there are acute, crisis situations that must be taken care of "now". I hope as the results of the E.I.P. are tabulated, the value of preventive intervention will be borne out.

One of the finest benefits of the demonstration project was the offering of a home visit by a public health nurse to every mother and new baby born at Mid-Maine Medical Center, Seton Unit. We have now taken that concept state-wide, and DPHN is in the process of establishing a protocol for this at each hospital in Maine having an obstetrical department. The disadvantage will be the lack of PHN's to implement this fully, but the concept removes any onus of "singling-out" mothers for this service. Responses to the hospital staff on the results of the home visits help them to feel "connected" to the referral process. However, we often felt we were unable to enlist the full support of the hospital nurses, and in part attributed this to the fact that the director of nursing (vice-president for nursing) had not been included and her support solicited prior to the start of the project.

In the early months of the project, the service co-ordinator did not have direct, daily supervision, so she did not enjoy the benefits, encouragement and guidance that this would have been able to provide her. I offered this service a few times but it generally was not accepted. However, in the last several months this need has been filled by a supervisor from the Bureau of Children With Special Needs, and the smooth, operational flow has been obvious.

I had no direct involvement with the Service Assessment Team, but staff public health nurses would express their views to me. The contacts, and therefore, the networking that took place among the service community was invaluable both for the team process and in every day functioning of the PHN's work load. However, they often said that the team did not meet when the families really needed it and frequently by the time the family "came to team" many services were already in place. The team process at that point often seemed a "rubber stamp". The professional contacts made, remains as the strongest link in the team process.

For me, two glaring needs of our service care resources emerged as being hardly ever easily obtained. The first is the lack of affordable, accessible transportation to many of our patients, especially our young mothers in rural, socially isolated areas. This lack keeps them from taking advantage of existing programs & resources. The second is the lack of safe, comfortable respite care for parents of handicapped children, for young mothers with babies who need a little "time out", or to continue their education. We need to become farsighted enough to realize that a reduction of the stress of daily living on parents who are having difficulty coping (whether the cause is biological, established or environmental) will help reduce the likelihood of child abuse and neglect. Parenting classes and parent support groups are essential, but they don't address the whole problem.

Looking back, I realize my feelings about the Early Intervention Project are ambivalent. I do know that I have learned so much from watching the process evolve, and that if we could begin anew the 3 year project, knowing what all of us now know, it would be a far different picture now.

Thank you for giving me the opportunity to express this.

Sincerely,

Joyce K. Hubbard, R.N.

JKH:nl
cc: Helen Zidowecki, Director
Debbie N.Johnston, BCSN
Jeanne Rough, PHN II

mid-maine
medical
center
WATERVILLE MAINE 04901

BETON UNIT - CHASE AVENUE
PHONE: 872-4305

Children's
Developmental
Project

EDMUND ERVIN, M.D. PROJECT DIRECTOR
RONA ROSENTHAL PROJECT CO-ORDINATOR

MEMO

TO: Ms. T.acy Haller, EIP Service Coordinator

FROM: Edmund N. Ervin, M.D.

DATE: May 8, 1987

SUBJECT: EIP Evaluation Component and Final Report

Apart from the stated goals of the EIP Project the one significant benefit was the development of philosophy and attitude regarding the importence of at risk screening among nursery personnel. This effort has now become an established feature of nursery protocol.

The importance of such a screening at the onset is of paramount importance.

NARRATIVE REPORT

with

Case Examples

of the

EARLY INTERVENTION PROJECT

A Handicapped Children's Early Education Project
of the U. S. Department of Education

conducted under the auspices of the

Maine
Interdepartmental Coordinating Committee for Preschool Handicapped Children

in conjunction with the

Department of Mental Health and Mental Retardation
(Augusta, Maine)

and the

Mid-Maine Medical Center
(Waterville, Maine)

July 1, 1984 - September 30, 1987
(Grant No. 008400798, Project No. 024BH50008)

Prepared by

Lou Parnell, Service Coordinator
and
Tracy Haller, Cooperating Service Coordinator
Bureau of Children with Special Needs
Department of Mental Health and Mental Retardation
State House Station # 40
Augusta, Maine 04333

CONTENTS

Introduction

Issues Related to Information/Acceptance/Communication

Structure and Management 2.
Acceptance of the Project 5.

Issues Related to Primary Design Components

Hospital Screening 7.
Pre-natal Assessment 8.
Home Visits 9.
Service Assessment Team Referrals 10.

Issues Related to the Service Assessment Team Process

Positive 14.
Negative 17.

Conclusion

Discussion of Statistics

Introduction 20.
Total Births and Total Screened 20.
Risks Identified: In-hospital 21
Home Visit Status 22.
Risks Identified: Home Visits 22.
Disposition of Cases 23.

Appendix

Criteria for Referral Definitions 25.
Established risk 25.
Biological risk 25.
Environmental risk 26.

NARRATIVE DESCRIPTION OF THE DYNAMICS OF THE EARLY INTERVENTION PROJECT * WITH CASE EXAMPLES

(* Note: Although the official name of the project was "Preventive Intervention Project," it was informally changed at the local level to "Early Intervention Project" - EIP - because of confusion over the term "prevention.")

Introduction

The design of the Early Intervention Project (EIP) was based on the premise that coordinated, multidisciplinary service planning of early intervention activities is more productive than "single discipline" service planning. Additionally, the project was based on the well-researched belief that early intervention (and prevention, in terms of "at risk" factors) activities are both more effective and more efficient than addressing problems after they are full-blown.

In order to examine fully the concept of coordinated service plans developed from a multidisciplinary approach, the idea of "more productive" needs to be defined. If the following questions can be answered in the affirmative, the outcomes are viewed as "more productive."

Does the coordinated early intervention and service planning -

- provide a more complete picture of risks for infant and family;
- enable services to be provided in a more efficient and timely fashion;
- elicit a higher level of parental involvement;
- reduce duplication of services for any one family; and
- reduce the chances of confusion and improve communication between and among agencies providing child and family services?

If the answer to any of these questions is a negative, than the reasons underlying that response must be examined before the model, or specific component of the model, is discarded as non-productive.

The following narrative will attempt to examine the EIP with the above concepts in mind, albeit subjectively. Discussion of the project will be divided into five areas:

I. Issues related to information/acceptance/communication
II. Issues related to primary design components
III. Issues related to the Service Team component
IV. Conclusions
V. Discussion of statistics
Appendix

Each of these areas will be examined in light of their strengths, weaknesses and changes over time. There will be some overlapping, since all project activities were, of necessity, interwoven.

I. Issues Related to Information/Acceptance/Communication

Structure and Management

In the formative stages of the project, two key factors played an important role in the smoothness of development, or lack of it. The project initially came under the auspices of the Maine Interdepartmental Coordinating Committee for Preschool Handicapped Children (ICCPHC). It is rare to find state departments sharing in the planning and execution of a federally-funded project, because such collaboration inevitably means the relinquishing of control and decision-making by the applicant agency and requires each participating agency to cooperate and compromise on a wide variety of issues. In the course of achieving concensus, long struggles, lengthy discussions, and a plethora of committee meetings can be guaranteed! On the positive side of collaboration, of course, are the many exemplary ideas and opinions, from a wide range of perspectives and professions, that can be melded together to produce an outstanding and unique "product."

Under the ICCPHC a Zero-to-Three Committee (ZTC) had primary responsibility for project oversight; the same positive and negative features of a multiagency, multidisciplinary group described above applied to the ZTC. At the local level - the community and region in which the EIP actually functioned - a Working Group (WG), made up of administrators or supervisors of various medical, health and social service providing agencies in the area, served as a steering committee. Membership in this group was identified after the EIP was initiated at the Mid-Maine Medical Center; this membership varied somewhat during the course of the project and the responsibilities of the group were never clearly enough defined.

Another interagency, collaborative factor affecting the operation of the EIP was the fact that the entire state of Maine is served by sixteen Preschool Coordination Site programs, overseen by the ICCPHC

The three oldest of these programs began in 1977; statewide coverage was achieved by 1983, with the program encompassing the Waterville area (Project PEDS) being one of the newest. At the time the EIP was initiated, these projects' focus was on the coordination of services to 3-to-5 year old handicapped children - they were not authorized or funded to serve "at risk" children, nor to provide any services for 0-to-3 year olds other than rudimentary screening and referral. (At the time of the writing of this report, all 16 projects are in the process of conversion to "0-5 Coordination Sites," under the provision of P.L. 99-457.)

As established, funded (with a combination of state and federal dollars) and operated, each Preschool Coordination Site is governed by a "Local Coordinating Committee" (LCC) of state and private service providing agencies and individuals, and parents of handicapped preschool children. This group prepares budgets, establishes priorities within the ICCPHC's overall policies, controls spending and hires a project coordinator and other related staff. The formation of these LCCs preceded the initiation and funding of their programs, and (as mentioned above) the network of projects is now 10 years old.

The EIP - in contrast - had a different relationship with the ICCPHC (through the Zero-to-Three Committee); served a population different by age and characteristics; related to a Working Group that was organized differently and later than Project PEDS' Local Coordinating Committee; and was funded with federal funds only. Yet many of the Working Group members also served on the LCC! Therefore, the first task of EIP staff was to develop a sense of local interest and ownership in the project.

This was a difficult, though necessary step. Without local participation and support, the Early Intervention Project clearly would not be able to function at all. Much time was spent by EIP staff - particularly during the first six months of the project - in dealing with public information, public relations and developing a positive community awareness of the project's purposes and intentions. Ultimately, acceptance of the project became basically positive. The Obstetrical Nursing Department Head at Mid-Maine Medical Center was entirely in favor of the project and helped its staff from the beginning. The hospital's Social Work staff was also actively involved throughout the project, as were key Pediatric staff of the hospital.

On the other hand, very few <u>other</u> hospital and community people even knew of the project's existence. Office space was provided in the hospital for two of the project's three years, but it was never adequate nor as inexpensive as that provided to Project PEDS. The Working Group was made up of various members of community-based service providing agencies and hospital staff and their time was

donated by their agencies. General knowledge of the project in the greater Waterville community, however, was slight.

As mentioned earlier, the role of the Working Group was never clearly defined and was perceived differently by its own members as well as by members of the Zero-to-Three Committee and the ICCPHC. The Working Group wrestled with such issues as -

- What is the relationship between the WG, the LCC, the Zero-to-Three Committee, the ICCPHC and the project staff?
- What authority, if any, does the WG have to revise the "Zero-to-Three Policy Manual" that had been developed earlier by the ZTC?
- How much authority or "governing ability" does the Working Group have over project staff and activities.

A recurring theme of the Working Group throughout the project's three-year life span was that of "too many chiefs; not enough Indians." Managers, coordinators and over-seers of the project also seemed in greater supply than did direct service, "front line" staff! Despite these problems, the Working Group was an active, dedicated body with a real desire and willingness for the project to succeed. Similarly, the Service Assessment Team (SAT) - composed of actual direct care staff of the various service providing agencies in the region - was a real strength of the project. Team members met for 2.5 hours twice a month, with their time donated by their agencies; in its initial operation the SAT was also involved in extensive training in such areas as team functioning, community roles, policies and practices with clients, networking, etc. "Turf" issues were either left outside the door of SAT meetings, or presented for team resolution. SAT members helped designed the team meeting format, assisted in the design of client information forms and case plans, and helped formulate agreements between the agencies represented by team members. Over time, the team solidified, with only two "drop-outs" during the life of the project (due to agency overload).

The project's budget allowed for ample training of staff, local agency representatives (such as those on the Service Assessment Team) and Working Group members. Training involved the importation of persons to provide specific technical assistance, as well as the attendance of individuals at regional, state and national presentations and conferences related to early intervention. This was a definite asset and should be a strong component of any similar pojrect. A highpoint of the training was a day-long workshop for hospital staff and community service providers with Dr. T. Barry Brazelton and his team from Boston Children's Hospital, on newborn screening and assessment.

Acceptance of the Project

In the beginning, parents of newborns readily accepted the idea of home visits by a Public Health Nurse. Level of acceptance was close to 100%. Project staff spent time with mothers (and, whenever possible, fathers) in the hospital, before and after delivery, describing the project, completing the desired in-hospital screening, and obtaining the necessary consent for the home visits. This process was very time consuming and was not actually within the original project design. However, it proved to be a necessary and effective approach to parental acceptance - a typical comment was that of one parent, who said, "I wish there'd been something like this arranged when my other children were born." (The fact that the Assessment Coordinator was a Public Health Nurse was a contributing factor in obtaining parental acceptance and in arranging and coordinating the home visits, which were conducted by the PHNs regularly assigned to the project's geographic area.)

It took approximately one year of constant effort before the hospital's nursing staff began including the EIP Assessment process in their hands-on work with obstetrical patients. Although verbal support for the project was expressed fairly readily, actual participation or the revision of existing nursing routines was slower to follow. Turnover among the various nursing directors' and supervisors' positions during the life of the project; the hospital's internal organization of its nursing department; and problems of dealing with three complete shifts of floor nurses all contributed to delays and discrepancies from the original project design. In truth, the illness-related absence of the Assessment Coordinator for a six week period around the middle of the project's three year duration precipitated the active involvement of hospital nurses in the screening process. Prior to that time, the Assessment Coordinator had done a majority of the actual screening herself, by default.

With this impetus, the hospital nurses - who had easily accepted the concept of the screening - became active participants in this area of the project's activities. They also began to verbalize their feelings - that for years they had had "gut feelings" about potentially dysfunctional families, particularly in the area of Environmental risk , without having a person or a resource to whom referrals of these families could be made.

As stated earlier, acceptance of the Assessment phase of the project (consisting of the Hospital Screening and the Home Visit) was almost universal. At the conclusion of the Home Visit process (which might involve more than one actual visit), the Public Health Nurse making the visit would request parental consent to refer the family to the Service Team, if she had observed a handicapping or "at risk" condition, of if she felt that an analysis of the Hospital Screening and the Home Visit components by the Assessment Coordinator would

result in a high enough score on "weighted risk" chart to justify a referral. Acceptance of "referral to the team" was generally lower than acceptance of the Hospital Screening/Home Visit component. Hesitant families required more explanation and time to consider the request; some refused all together.

When consent was not forthcoming, the case could be referred to the Service Assessment Team without any personally identifying data, as an "anonymous" case. This permitted the referring PHN to obtain ideas and suggestions from the other service providers (about potential services and/or coordination thereof, or approaches to hesitant families) without violating the family's privacy.

When young, single mothers did not consent to SAT referral, the reaons frequently involved their fear of "state" services; concern that they would lose some of their independence if a referral were made; fear that services they were "illegally" receiving would be terminated if the circumstances of their living arrangements became known to officaldom, etc. The following case illustrates a typical refusal.

> Case 006 (Refusal) - This case involved a single teen parent, who accpeted the Assessment phase (Hospital Screening and Home Visit) readily. The risk factors were all in the Environmental category (single, teen-age parent under economic stress). The mother was hesitant to become involved in the team process, following the Home Visit by the PHN. The Service Coordinator made four home visits before the Mother would allow her into the home to explain and discuss the team process. Once inside the home, the Service Coordinator was received warmly; however, the Mother would only allow an anonymous referral to be made to the Service Assessment Team.
>
> Team recommendations included referral for economic assistance, Family Independence Services (a program of DHS for new AFDC mothers under age 20), transportation and linkage with a local program aimed at enabling teen parents to complete their highschool education. The Mother was eligible for these services, and they were started (although transportation was only available for the educational component, not for other purposes, in the area in which she lived).
>
> Things appeared to be progressing smoothly for a few weeks, when suddenly Mother was not at home for several consecutive appointments. As project staff, the Public Health Nurse and Family Independence Service representatives attempted to regain contact, partial information was obtained from neighbors, concerning a boyfriend moving in, then moving out, the client moving in with her parents, etc. Eventually, Family Independence Services again made contact, but all further services were refused by Mother, without explanation.

Sometimes refusal of SAT referral was occasioned by external pressures. Case 015 accepted the idea of the project whole-heartedly. However, her mother (the infant's maternal grandmother) was heavily involved with the Department of Human Services in a custody dispute over parental rights; even with the involvement of multiple service providers and a high level of coordination between them, the child's mother eventually refused all services and moved back home for fear of losing her baby.

Case 034 was one in which Mother had been a very active participant with the Service Assessment Team. She attended every team meeting in person; many service providers were involved with an exceedingly high degree of coordination, elimination of duplication, etc. However, Mother had had parental rights terminated on three of her previous children, and the possibility of her keeping the new baby hinged on her willingness to follow through with the recommended services. Her agreement to each SAT recommendation was preceded by the question: "Will this help me keep my baby?" Although it might be preferred that she participated actively because of an inherent understanding of the project's value, clearly an absence of a coordinated service delivery system would not have contributed to her being allowed to keep her new child.

II. Issues Related to Primary Design Components

Hospital Screening

No attempt will be made here to provide a detailed description of the project's original design. This was done by MATRICES Consultants, Inc. in a report of February 20, 1986. Here, an attempt will be made to describe the effects of that design on hospital staff, service providers and the clients served.

At the hospital level, as stated earlier, screening by hospital (as opposed to project) staff had a slow start. The original idea was to have the Hospital Screening done by nursing staff as part of their routine, daily activities. The slow start was due in part to the hospital staff's lack of familiarity with the screening forms; an existing paperwork overload; changes in hospital administrative personnel; and a reluctance on the part of the Assessment Coordinator to "let go" of responsibility for the screening for fear of "losing" some of the families in the process. Over time, the hospital nurses assumed more responsibility as they became more familiar with the forms and concept of the project. Involvement of hospital staff would have been accomplished much sooner if the project had been fully explained to and endorsed by the hospital prior to its beginning. (In fact, the grant was received by the Department of Mental Health and Mental Retardation before the "host hospital" was selected, so clearly there had been no involvement of the hospital staff in its design or in the application process.

As the hospital nurses assumed more responsibility for the Hospital Screening (and the initial explanation of the project to the newborns' parents) the acceptance rate dropped to about 80%. Nearing the end of the project period, the acceptance rate dropped to approximately 50%. This appears to have been related to confusion about whether the project would be continued with state funding and finally was directly related to the information that the project would be terminated on June 30, 1987. (At times of an increased number of births, acceptance rates declined too, because of the increased work load of the nursing staff.)

Towards the end of the project, changes in the staffing of the hospital's Social Service Department resulted in an agreement whereby that department would conduct the Hospital Screening of those clients in the Environmental risk category, while the hospital nurses completed screening for those in the Biological and Established risk categories. The project's Assessment Coordinator was responsible for overseeing the transfer of cases (and accompanying paperwork) from within the hospital to the appropriate Public Health Nurse for the conduct of the Home Visit components of the Assessment phase.

Throughout the project there remained confusion about who was ultimately responsible for the conduct of activities - project or hospital staff. The aforementioned lack of involvement by the hospital in the project's design contributed to the lack of its full integration.

Although thought was given to revising procedures so that initial screening occured outside of the hospital, this idea was not adopted. Through the Hospital Screening process families became much more aware of services available to them, as the project was initially explained to them. Too, the level of consciousness regarding the concept and practice of "preventive intervention" was raised considerably by in-hospital screening, in both clients and hospital staff. Revisions in the Public Health Nursing screening form, occasioned by the development of the project, made it possible for obstetrical and nursery nurses to record and report their felt - but not easily identifiable - concerns about mother/infant development. A definite recommendation for future similar projects would be to increase the level and extent of education - for both hospital staff and clients - in preventive intervention, use of assessment procedures, issues related to parent-infant bonding, range of community resources, etc.

Pre-natal Assessment

The Zero-to-Three Committee's policy manual called for a prenatal assessment phase. This was not incorporated into the EIP design at the start because it was felt to be too large an undertaking. In the final 15 months of the project, EIP staff contacted personnel of the hospital's Prenatal Clinic. Some of these individuals were already familiar with the project from working on the Obstetrical floor or

from service on the Working Group; additionally, project staff contacted a number of the area's obstetricians. Referrals of high risk pregnancies were received and service planning and coordination was begun immediately, as illustrated in the following case:

> Case 033 (Prenatal) - The referral was made by the hospital's Prenatal Clinic and the hospital's Social Work Department jointly, in the category of Environmental risk - primarily because of concerns about the mother's emotional stability. Multiple service providers, including Child Protective Services, were already involved with the family. With all service providers present at the Service Assessment Team meeting, plans were made with hospital staff for extra support at the time of birth; existing providers coordinated their efforts; and a few overlaps in services were eliminated. The time between the original referral and the first team meeting was only three days.

For the same reasons cited earlier (potential and then announced termination of the project) prenatal referrals declined prior to the project's end; additionally, the Assessment Coordinator's position was reduced to 1/3-time in the six month's prior to the end of the project, which was not sufficient to cover both prenatal and post partum referrals. It was clear, however, that many of the conditions that would result in a referral after delivery were identifiable during the pregnancy - this was particularly true in the Environmental risk category.

Home Visits

The Home Visit component of the Assessment phase had some obvious pluses and minues. On the plus side, more families were linked with health care providers. Feedback from families clearly indicated that even totally intact, "no risk" families greatly benefited from the contact, education and reassurance they were provided by the visiting Public Health Nurse. Potential problems that might have been unidentifiable or masked during the Hospital Screening frequently surfaced during the Home Visit. Case 029 illustrates this point.

> Case 029 - This involved an intact family unit with the father working and financial support systems in place. The parents' first infant had died at 3 months, a victim of Sudden Infant Death Syndrome. The parents took their second baby home on an apnia monitor, as the infant had experienced some respiratory distress, and readily accepted the Public Health Nurse's visit.
>
> Following the Home Visit, the PHN felt some concern, even though everything seemed to be going well. Because of her intuition, coupled with the Biological Risk factors, a referral to the Service Assessment Team was made with the family's full consent. When the presentation was made, the team raised questions concerning the parents' completion of the grieving process (for the first child) and the parents' concern for the health of the second

child. (The mother kept a sign on her door, saying: "If you have a cold, please do not come in.")

Medical reports were reviewed and the team recommended further tests, personal linkage of the Public Health Nurse to the family's physician, and the establishment of a link with the nearest mental health counseling service. The Service Coordinator reviewed emergency procedures with the family and worked with the mother on issues surrounding not only the grieving process but also "anniversary dates" linked to the first child. The family felt comfortable with the idea of counseling, should the need arise. Both the PHN and EIP staff maintained contact with this family for several months, by which time both the family's and the child's development seemed to be progressing in a healthier fashion.

Without the project's capacities, it seems unlikely that the mother's emotional needs would have been identified or responded to. Services would most likely have been limited to the medical care required by the infant. The struggle of the family to bond with the second infant, while fearing a repetition of the loss of the first child - if unidentified - could easily have produced a "classic" case of Failure-to-Thrive Syndrome.

A clear positive result of providing Home Visits to the families of all newborns (instead of the previous practice of visiting only those with clearcut Established or Biological risk status at birth) was the increased energy provided to the Public Health Nurses by being allowed to visit some "well" families as well as those with problems. Repeatedly, PHNs indicated how helpful it was to their personal and professional self-concepts to be enabled to see healthy babies and families, as well as those in varying degrees of dysfunction!

On the minus side of the Home Visit component, there was disagreement regarding the issue of who should have primary responsibility for conducting the visits. As originally designed, the project called for all home visits to be conducted by Public Health Nurses, and this element remained unchanged throughout the project. Objections to this practice appeared to be based on stereotypical perceptions of the public health nursing profession. Concern was expressed that this exclusive involvement of PHNs might cause a greater perception of the project's offering a "medical model" of preventive intervention than a multidisciplinary approach would. There were also concerns expressed that Public Health Nurses - in general - might be less likely to perceive emotional and psychosocial needs of infants and families than might representatives of counseling and social service professions.

Off-setting these concerns was the fact that all of Maine's Public Health Nurses have actively participated for the past 5-6 years in training opportunities in the areas of infant mental health, preventive intervention, trans-disciplinary service coordination, etc. It has also been documented that, in many cases, any "state worker"

may be viewed negatively by a family being visited. As noted, no change in the Home Visit staff was made and certainly the positive value of these visits greatly exceeded any imagined weakness occasioned by their "single discipline" execution.

Another problem was the sheer work-load involved in visiting every newborn, instead of only those who exhibited clear medical or birth-related risks or handicaps. Actually, during the period of the project, the number of Public Health Nursing positions statewide slightly decreased while PHN responsibilities increased. Although it is anticipated that the benefits of "100% home visits," as they are documented, can eventually be used to increase overall PHN staffing, during the interim period until new positions can be added to departmental budget requests and successfully advocated with the state legislature (a process that may take several years) work overload problems are inevitable.

Service Assessment Team Referrals

The project design assumed that a reduction of overlapping responsibilities among service providers, coupled with increased support of existing agencies' staff through networking and coordination, would permit increased service productivity. Too, the designers had not wanted to add significant numbers of new service providers because of the inevitable problem in trying to continue the new positions with state dollars at the expiration of the project period. Although it could be demonstrated that productivity and morale did improve, increased case finding and referral procedures also increased work loads of many agencies. As a result, many participants in the project felt that they were being asked to function within an unrealistic framework of expectations.

As parents' acceptance of hospital screening decreased during the last half of the project, so did related home visits. Accordingly, the geographic area served by the project was expanded to match the entire catchment area of Project PEDS (the regional 3-to-5 year old coordination program). This action helped improve the blending of the two programs' purposes and activities, but also produced or reinforced some negative side-effects, reported by PHNs during the Homee Visit process: (1) As the geographic area increased, the Waterville-area-based SAT of providers did not represent agencies in the more distant portions of Project PEDS' area. (2) More high risk referrals were obtained from smaller, more rural hospitals than from Mid-Maine Medical Center (Waterville) where the project was housed. (3) Often the parents needed to be "talked into" a referral to Team; going to the meeting took a lot of PHN time and the resulting service plan was often seen as merely repeating what the PHN had already instructed the mother. (4) Teen parents didn't want "a lot of people" involved in their lives; the PHNs often felt fortunate if a teen parent would accept her alone. (5) Problems of babysitters, transportation, etc. were often too difficult or impossible for a

parent to manage. (6) As project activity declined, prior to termination, only one team meeting could be scheduled, and the PHNs wondered "Why bother?"

In an overall review discussion with the Public Health Nurses serving the project area (March 1987), there seemed to be a general feeling that the Service Assessment Team meetings should have been called when the family and/or the health and medical care providers felt a need, rather than according to an "artificially determined schedule." The nurses seemed to feel that they had been asked to serve the team, rather than having the team available to serve them and their families. Of course, calling interdisciplinary team meetings only at the request of a physican or nurse would seem to conflict with (if not totally negate) the underlying point the project attempted to document - that interagency, multidisciplinary assessment and service planning activities can be more effective than "single discipline" ones! Perhaps the eventual answer, in another situation, would be to have "primary" responsibility for calling a SAT meeting rest with the visiting PHN, but permit and encourage the option of "secondary" meetings on the request of anyone familiar with the case or with a particular constellation of infant-and-family problems.

The design of the process of referring cases to the Service Assessment Team (SAT) and the team concept itself were basically sound. Following the PHN's home visit(s), it was planned that a joint decision related to the need for a "referral to Team" would be made by the PHN, the family, the Assessment Coordinator and the Service Coordinator. In some instances, this was accomplished as designed. Occasionally, the Public Health Nurse was the sole decision-maker. The ultimately-developed "rule of thumb" was: If the risk or handicap is clear-cut, make the referral. If the need for a referral is not clear, or borderline, consult with the Assessment and Service Coordinators. Due to the number of births from within the project area, no effort was made for the team to review all Hospital Screening and Home Visit results. (When prenatal referrals to Team were made by a primary medical care provider, or by the hospital's social work department, the PHN was considered a secondary resource and was still included in the decision to refer.)

The Service Assessment Team met approximately twice each month, and was prepared to discuss more frequent meetings, had the need arisen before the project's end. The first SAT meeting did not occur until sixteen months after the project's official starting date (July, 1984), ten months after project staff began work (January, 1985) and two-and-a-half months after the Hospital Screening component was implemented. Referrals averaged 3-6 each month during the "height" of project activity, and dropped to 1-2 per month by the fall of 1986, as the project began winding down.

Over time, it appears that the decision to "refer to Team" (or not) fell solely in the arena of Public Health Nurses (in the field)

and the Assessment Coordinator (herself a Public Health Nurse). There was also frequently a significant time lag (several months in some cases) between an infant's birth and a referral to the SAT. In reviewing alternative possibilities, the following retrospective suggestions were made by SAT members:

(1) The attempt to measure significant differences in outcomes between families referred to the Team and families initially seen only by a PHN should not have been attempted; rather all families meeting risk/handicapped criteria should have had access to SAT planning capacities. (2) Any service provider should have been enabled to make Team referrals, rather than only PHNs. (3) The primary care provider - most frequently a PHN - should have secured the necessary parental consent for Team referral, rather than the Service Coordinator having to make a "pre-Team" home visit for this purpose. (4) Not all at-risk families should be reviewed by the Team, but only those where there was a definite need for service coordination or a need to generate ideas and new approaches to problems. (5) It would be helpful if the Team were able to meet more readily and flexibly, rather than on a pre-established twice-a-month schedule.

Rather than the SAT having a basically "fixed" membership for all families, it might have been better to have an ad hoc team of providers involved with a particular family, assembled at the request of any single provider representative. Similar in function to the SAT model, such teams could meet to insure that communications between agencies was adequate, to identify new services needed and possible overlooked resources, to avoid duplication of effort, and to plan strategies for intervention in resistant or complex cases. This approach was tried in the final months of the project, and appeared to work well. However, by that time the providers involved had worked together for approximately 18 months and had gained confidence in the abilities of the Service Coordinator as well as an understanding of her role. It is believed that starting in this way from the outset of the project - with a variety of ad hoc teams and an "unkown" coordinator functioning in an "undefined" role - would have been a different proposition all together!

III. Issues Related to the Service Assessment Team Process

Positive

In terms of service planning, identification and/or development of resources, and delivery of services to families, there were several pluses resulting from the team approach.

1. A team approach meant that no one person or service providing agency had sole responsibility for developing the case plan. With the variety of disciplines present, the family needs were viewed from many angles, with less likelihood of missing any important elements. This result was most noticeable when there were many service providers involved, or when the issues of a case were complex.

> Case 023 was a family with five children, living in cramped housing. Their needs including securing more adequate housing, achieving a more functional literacy level, nutritional education, substance abuse counseling, better health care, dental care, financial support, transportation assistance, and improved life-coping skills. Service providers from every imaginable discipline had been linked with the family at one time or another, prior to their involvement with the Early Intervention Project, yet most providers had never previously coordinated their planning with each other.
>
> In order to assist the family in dealing with its needs, service recommendations needed to be carried out in a fairly specific order. The SAT first had to decide which services should take priority, and establish appropriate time lines. (For example, the dental problems had affected the mother's health to an extent that it interfered with her literacy education. Dental care required arranging special transportation to a clinic 40 miles distant.) Health needs of the mother and children were also paramont, followed by financial assistance and housing. Each service provider had not only a voice in the overall planning, but also was able to determine when each service or assistance should begin and/or end. It is difficult to see how this degree of coordination could have been accomplished without the Team process.
>
> In the process of obtaining adequate housing, the family moved to another provider area. Because the Team had developed a solid network among the various agencies, the family was quickly linked with providers offering similar services in the new area, who agreed to follow the original case plan.

2. The team provided a "vehicle" for networking of services; in many cases this assisted in their more expedient delivery. Too, new procedures, policies and problems related to service delivery could be diseminated more easily and quickly than would otherwise have been the case.

Case 007 illustrates this point. At birth, the baby exhibited some hypotonia, but appeared fine at discharge. The family was referred to the Team not only because of the early hypotonia but also because the mother needed more adequate housing; was having difficulty in securing general and fuel assistance from her town; was single and unemployed; and - this being her first child - had no baby clothes, equipment or furnishings.

The various involved providers worked with Mother to meet her immediate financial needs, EIP staff assisted her to obtain more adequate housing; and the PHN continued home visits. It was agreed that if any provider noted any developmental lags in the infant, an immediate referral would be made to the Child Development Clinic at Mid-Maine Medical Center. At approximately 7 months, a lag in head movement was detected. Because key staff of the CDC were on the Service Assessment Team, the referral was accomplished without delay or question. In addition, during this 7-month period, the family had moved out of the project's service area and then back in again! The case plan and the linkages established by the Team with a Child Development Worker and an Occupational Therapist were easily transferred between jurisdictions and back again.

3. Case managers were agreed upon by team members and the family.

4. Team members learned about various services and support systems which normally would have been known to only a few providers. This not only increased their productivity but improved their morale by making them feel less isolated in their efforts to help families with special needs.

Case 009 This family fell into the Environmental risk category, with economic stress being the primary risk condition. Following the Hospital Screening and Home Visit, the family met with the Service Coordinator for further assessment of family needs and possible services. The parents were in favor of a referral to the Service Assessment Team as soon as the project was explained to them.

At the Team meeting, it was established that the family were in temporary need of AFDC, Food Stamps, WIC and Medicaid but did not qualify for the eligibility criteria, being one of many families that "fall through the cracks" of existing social service programs. However, the family was referred to the local Community Action Program's "information and referral" service which was represented by a member of the SAT, and to the Maine Job Service. There it was determined that the family <u>was</u> eligible for a special program offering training, placement and subsidized employment. In a relatively short period of time, the father was employed. Follow-up contacts indicated that things had improved for the family and that the baby's early development was progressing well.

5. Almost all cases illustrated the fact that a team approach assisted in reducing overlapping efforts or services.

6. The Service Assessment Team mechanism enabled all service providers to agree on the best approach to such human service issues as "rescuing" a client vs. helping a client become more independent; how to respond to "resistant" clients; when it was advisable to suspend or slow down activity on a case due to a falling off of client response; and similar case management questions. The skills and knowledge of all team members were enhanced by these informal training opportunities and all Team members would agree to use the same approach to the client, thereby reducing the possibility of "cognitive dissonance."

> Case 010 involved a mother with multiple needs and required the involvement of many service providers. Dental care was identified as a major problem by the mother at the first team meeting; she described how hard it was for her to relate to other people because she needed restorative dental work so badly. She also needed transportation services and a car seat for the infant (mandated by state law).
>
> One of the providers delivered a car seat to the rural home where she lived, so that she could transport the infant in neighbors' cars when opportunities arose. Much effort was also spent locating "no cost" dental services, and a series of six appointments was arranged. The first was kept, but the mother did not show up for the second or third. Since there was no phone at her house, arrangements could only be made during home visits.
>
> Eventually, it was determined that the mother had not kept the other appointments because she was more fully occupied in being tutored for a driver's examination - and passing it - and was, as she put it, "dealing with other parts of my life." Accordingly, the Team decided to defer other services until the mother requested a reconnection with the project, as a way of helping encourage her sense of independence and responsibility. Clearly, in such an instance, concensus among all the involved service providers was essential.

Case 036 was somewhat different. Here the family appeared eager to participate in the plan that they assisted the Team in developing, but would not accept any services that were not home-based. It was subsequently discovered that the family had moved many, many times - thus escaping even those services that could be delivered to the home. Without the team process, it is likely that individual service providers would have continued to try to "do for" this family indefinitely, at the expense of other clients who might have appeared less willing at the onset, but perhaps more willing to follow through with actions.

Negative

There were negative aspects to the Team approach too.

1. At times the Team would "over discuss" or get side-tracked with tangential issues, especially when many agency representatives were participating. This problem was partially the result of lack of clarity concerning the role of the Service Coordinator, who had to both facilitate and direct the group's process.

2. There was concern that by the time a family case was brought to the Team, services had already been put into place. However, the ultimate task of the Team was not to recommend services for which the need was self-evident, but to provide coordination and input - in either a preventive or treatment mode - related to complex cases or non-routine issues.

3. The SAT often identified a need but was unable to effect delivery of a matching service, because -

- the service did not exist (e.g. financial assistance for middle income families);
- the service was already "over-booked" (e.g. child protective services, Homemaker services, etc.);
- the client was ineligible for the service (e.g. Family Indpendence Services were limited to mothers 19 and under);
- the client was unable to provide or obtain transportation to the site of the services;
- services could not be provided for a long enough period of time (e.g. under Child Protective Services procedures, transportation and Homemaker services could be provider while a case was "open" but not after it was "closed");
- the client did not follow through in accessing services that had been arranged.

It could be argued that these factors would apply whether a service coordinating team existed or not, and that the existence of the team merely meant that more people wasted valuable time mulling over something that couldn't be done. On the other hand, in a number of cases, the collective knowledge and ingenuity of the Team provided some avenues to services that might otherwise have been unexplored!

Some limited funds were available for purchase of specific direct services for individual clients; however, the Team needed to be extremely cautious in utilizing this money for fear that they would create dependency on an activity that could not be continued after the project ended. The most frequently missing or "over-booked" services include transportation, infant mental health services and Homemakers services.

Over time, the SAT became keenly aware of the impact that the lack of transportation had on case planning, and a major effort was begun to form a "transportation task force" for the central Maine area. This effort continued, even after the project period ended.

Project staff believe that - over a longer period of time - the SAT could have become an effective force for the development of new resources, through both local and state initiatives and funding.

4. If the project had expanded over time, the Service Assessment Team would have more fully addressed other issues. Following is an excerpt from a memo from the Team to the Working Group, the Project PEDS (3-to-5) Local Coordinating Committee, and the State-level Zero-to-Three Committee, written in November, 1986, with nine members present:

> "The Service Assessment Team, in lieu of its regular meeting, convened to discuss individual members' perspective on the SAT as it exists now and to make recommendations for future planning.
>
> A. For the present, it makes sense to keep the team in full operation until such time as the EIP phases out or phases into Project PEDSs (as a 0-to-5 system). Families could then be transitioned into PEDs through its case management system.
>
> B. The Team recommends, however, that the SAT be made available for <u>all</u> families in the catchment area with a child age 0-to-3 for whom a team approach might be beneficial. Under this plan, any service provider, acting as a referral source, would contact the Service Coordinator, secure necessary information and releases, and act as the primary liason with the family. The Service Coordinator would be responsible for contacting those providers not already members of the Team, and for establishing an agenda of cases for each Team meeting.
>
> C. The SAT members believe that not all at-risk families should be reviewed by the Team. Logical Team referrals are those families where there is a definite need for service coordination or a need to generate ideas of how to best meet complex family needs.
>
> D. Families who agree to a case plan and then do not follow through, are hard to locate, or refuse services should be given a lower priority than comparable families who are more willing to accept some responsibility. It is possible for the Team to spend too much time and energy attempting to gain the involvement of "resistant" families, whatever the reasons for the resistance.
>
> E. The amount of time it takes for a family to "get to Team" is too long. Team members believe this is due to having Team meetings only twice a month at a pre-determined date and time.
>
> F. In considering the organization of a "core" team vs. one made up of all "current providers" (i.e. related to a particular case), there are both pros and cons. In many cases, a fixed core team would likely involve members not involved with the family. Such members may be able to offer fresh ideas, as "uninvolved" persons. A core team, by guaranteeing interdisciplinary participation, more readily ensures viewpoints and potential linkage from all major disciplines; a "providers" team may not necessarily provide a cross-section of

disciplines. On the other hand, a permanent core team may be an unaffordable luxury, in terms of the time and manpower constraints of the individual participating agencies.

G. At present, coordination with Child Protective Services (DHS) is very difficult. Active involvement by CPS is essential; wiithout it, agencies are often coordinating services in a vacuum. The Team believes that this area is a critical one.

H. Caution needs to be taken not to assign Public Health Nurses as case managers unless it is logical to do so. All providers need room to say, "I'm overloaded." At the same time, the person most involved with the family is the logical case manager, and this person is frequently a PHN. Regardless, the SAT endorses the concept that parents should be their own case manager whenever possible and - regardless of the identified manager - be as active as possible in securing the needed, identified services."

IV. Conclusion

As one can conclude from reading this report, the basic design of the model appeeared viable. Most of the problems that occurred were either "mechanical" in nature or due to unique factors (such as personnel changes) that would not be universally experienced, if one were attempting to replicate or extract from this demonstration project.

Several specific thoughts are important:

1. Local support should be obtained, and a local committee established, prior to the hiring of staff. The local committee should be given full responsibility - as a governing body - to establish policies and procedures.

2. A mechanism should be established that would either offer reimbursement for being on the team or design the team so each agency will have equal time for presenting case studies.

3. Any philosophical issues involved in determining which discipline(s) should be involved in the Home Visit component of the assessment process should be resolved.

4. The participating hospital must have <u>full</u> involvement in planning, prior to the project's beginning, and should endorse it fully.

5. Extensive training to team members, all providers and hospital staff is essential; both substantive and process training was provided to Public Health Nurses, Obstetrical staff and Service Assessment Team members, resulting in tangible benefits.

6. The media should be utilized heavily to bring an understanding of the project to the public.

V. Discussion of Statistics

Introduction

The Early Intervention Project's evaluation component was designed to compare the effectiveness of coordinated, multi-agency, interdisciplinary service planning and delivery, aimed at handicapped or at-risk infants and their families, with more typical, "single discipline" referrals and activities . Through a process of random selection, families of infants delivered at Mid-Maine Medical Center, in Waterville, Maine, and who lived within the four-town "project area" were assigned to "standard" or "Team" groupings.

The "standard" designation indicated that any coordination of services would be accomplished by the Public Health Nurse assigned to that particular town, in the course of performing her normal nursing functions. "Team" designation meant that these families would be asked to participate in the planning process and service delivery arrangements of the Service Assessment Team. Both populations were provided with an in-hospital screening and a home visit by a Public Health Nurse, as part of the Assessment component of the project. (Families outside of the four-town project area were also provided with screening and home visit services, and essentially were treated in the same way as the "standard" population, but no effort was made to document activities or outcomes in these cases. From a demonstration standpoint, it was deemed more appropriate to try to compare two smaller populations - identified by random selection - within the same 4-town area.)

The project intended to collect information from both populations at various points during the project period and compare it. Information collected would relate to infant development, family-infant interaction, family functioning, and utilization of services.

Total Births and Total Screened

For the year 1986, there were 1,010 births at Mid-Maine Medical Center. 616 of these were born to families living outside the four town project area; 394 were within these towns, constituting "model" births.

Of this potential project population of 394, 103 (26%) were "screened without a report." This meant that -

- consent of the mother for participation in the project was not requested prior to her discharge, or
- the mother declined to give consent for her participation in the project, or
- some other factor prevented enrollment in the project (e.g. the mother gave the infant up for adoption, or the mother signed the consent form but later refused the home visit, etc.)

From the standpoint of the project, these families were termed "non-model" births.

Of the 394 "model" births, 291 (74%) were "screened with a report." This number represents the total number of families consenting and participating in the Assessment component of the project (hospital screening and home visit). The actual number of "screenings with reports" varied from month to month. Obviously, numbers were affected by the total number of births in a given month from within the project area. Too, in-hospital screenings were originally completed by the EIP staff; in mid-1986, the hospital obstetrical nursing staff assumed this responsibility. Although this was closer to the originally-intended project design, and the nursing staff benefited from the increased experience (and training) in newborn screening, the numbers of participating families decreased due to the OB staff's unfamiliarity with the forms and increased workload. Completed "screenings with reports" also decreased on weekends and holidays, due to decreased staffing patterns.

Two other factors negatively affecting the completion of in-hospital screening were the forced move (due to hospital expansion plans) of the project office from within the hospital to a store-front office in downtown Waterville - during the last six months of the project - and the subsequent realization that the State was not going to be able to continue the project at the end of the federally-funded grant period. The decreased visibility of project staff, occasioned by the move, reduced hospital staff participation; the inability of the state to continue the project also contributed to decreased interest and activity.

For reasons described elsewhere, the project was most fully functional only during one twelve-month period (Calendar Year 1986) of its three-year existence. Following is a chart of the percentage of the 291 "model" births screened during that period, by month:

TABLE I.

January	82%	July	94%
February	84%	August	88%
March	94%	September	71%
April	77%	October	70%
May	66%	November	54%
June	73%	December	35%

Risks Identified: In-hospital

Identified risks or handicaps were compiled under eight categories:

1. None
2. Established only
3. Environmental only
4. Biological only
5. Established & Biological
6 Established & Environmental

7. Biological & Environmental
8. All three

In addition to the specific guidance provided by these definitions, the "Environmental" category allowed the nurses to accomodate their "gut feelings" in not-so-ordinary cases of concern.

Of the 291 "screened with report" cases in 1986, 93 (32%) were reported as "None" and 198 (68%) were reported as exhibiting one or more risks or handicaps. The largest single category of these was represented by "Environmental only" with 50 (25%) cases.

Home Visit Status

The Home Visit statistics were generated from cases received by the Assessment Coordinator (as the result of the in-hospital screening) and referred to Public Health Nurses. Three categories were developed to help track the progress of the home visits: (1) Unable to complete (e.g. the parent initially consented to, then refused, the home visit); (2) Completed; and (3) Incomplete (for reasons other than refusal). During Calendar Year 1986, 281 Home Visits were completed.

Risks Identified: Home Visits

As a result of the Home Visit process, risks/handicaps were: (1) Confirmed, (2) Identified or (3) Negated (in relation to the outcomes of the in-hospital screening process). Many minor risks identified in the hospital were negated once a home visit was completed. The 68% of the "screened with report" cases reported as having at least one risk/handicap, as a result of the in-hospital screening, dropped to 50% after the completion of the Home Visit process.

Some of these risks/handicaps "disappeared" as a result of routine work of the hospital's Social Work Department prior to or immediately following discharge (as in the case of financial stress at the time of delivery being identified as an Environmental risk and being met by enrollment in a public assistance program). As was expected, risks/handicaps identified in the Biological category often showed decreased after the home visit, reflecting expected improvements in the mother's physical health (e.g. normal recovery from a Ceasarian section) after returning home. Some Environmental concerns also "disappeared" once the support systems available from the mother's family and friends were assesed during the Home Visit process.

On the other hand, the overall identification of risks/handicaps in the Environmental category showed an increase as a result of the home visits. This was partially the result of families' greater comfort in revealing or discussing "Environmental" concerns and stresses once they were no longer in the hospital, and partially the result of the greater opportunity for the "wide focus" perspective on a family's situation and functioning that the home visit provided.

The following chart reflects the identification of risks/handicaps through the in-hospital screening and the subsequent home visit:

TABLE II.

Risk/Handicap Category	In-Hospital Screening		Home Visit	
	#	(%)	#	(%)
1. None	93	(32%)	140	(50%)
2. Established only	4	(1%)	2	(1%)
3. Biological only	40	(14%)	3	(1%)
4. Environmental only	74	(25%)	123	(43%)
5. Established & Biological	0	0	0	0
6. Established & Environmental	2	(1%)	2	(1%)
7. Biological & Environmental	76	(26%)	10	(4%)
8. All three	2	(1%)	1	(-)
TOTALS	291	(100%)	281	(100%)

Disposition of Cases

Recording the disposition of cases served to illustrate activities subsequent to the home visit; the categories were designed to identify a variety of circumstances, as follows:

1. Team Referral Made - This category assumed that either risk/handicapped factors had been identified and confirmed through the two phases of the Assessment component, or that a nursing diagnosis (requiring a response) had been made, resulting in parent permission for a referral to the Service Assessment Team.

2. Risks: Team Referral Not Made - This category meant that risk/handicapped factors had been identified and confirmed but that for one of a number of reasons the family had not been referred to the Team. Primary reasons would be: parental refusal for a Team referral, despite their having consented to the home visit; the identified risk factors were deemed too insignificant to justify a referral; or the family had been randomly selected as a "standard" (as opposed to a "Team") family.

3. No Risk - When no risks were identified in either the in-hospital screening or the home visit, it was still possible that continued involvement with the case could occur. Such involvement might include an anonymous team discussion (for team training purposes), continued involvement by a Public Health Nurse, or later closure. (Even with no risks identified, Mother might request additional PHN visits.)

Approximately 23 families (16%) of those identified with risks/handicaps were referred to the Service Assessment Team; 34 families (24%) received continuing PHN contacts; 2 families (1%) receiving only monitoring; and 82 cases (58%) were closed with no services. Many of the closures were occasioned by the risks deemed too insignificant for services in the "real world" context of the project (e.g. a mother who smoked), or because necessary services and/or support systems were securely in place and there were no continuing medical or physical health related problems evident.

In looking at the statistics, it might be concluded that the highest value of the Home Visit activity was to uncover "hidden" Environmental risks/handicaps that had not been revealed through in-hospital screening. However, of those identified with risks following the home visit, half were dismissed as "insignificant" or with risk conditions well under control. Also, the 16% referred to Team could have been families where the risk was <u>either</u> identified in the hospital or through the home visit; only tracking "specific" families through the system could this distinction be determined.

More significantly, the primary value of the home visit was to reinforce the importance of continuing attention to health care issues in the raising of an infant, and to provide "health education" in as personalized and non-threatening a manner as possible. The project staff felt this represented the essence of "preventive intervention," in terms of reducing the likelihood of future problems.

APPENDIX

Criteria for Referral Definitions

Primary or other caregivers should consider referring to early intervention programs those children whose developmental or medical patterns fall within the broad or more specific limits of risk, or who are experiencing developmental delay of unknown etiology. The criteria for referral may be based on parents' needs as well as the needs of the child.

Established risk

Referrals to early intervention should be considered for those infants and children who are at established risk and whose early aberrant development is related to diagnosed medical disorders.

Established risk conditions include, but are not limited to, the following kids of disorders:

- Down's syndrome
- Hydrocephaly
- Spina bifida
- Cerebral palsy
- Orthopedic problems
- Medical concers that are expected to impinge on developmental progression
- Cleft lip and cleft palate and/or other congenital anomalies
- Hearing and vision impairments

Biological risk

Referrals to early intervention should be considered for those infants and children presenting a history of prenatal, perinatal, neonatal and early developmental events suggestive of biological insult(s) to the developing central nervous system.

Biological risk conditions include, but are not limited to, the following:

- Prematurily compounded by psycho-social and/or health problems, such as:
  - * low birthweight in conjunction with a low APGAR at 5 minutes
  - * respiratory distress syndrome
  - * small for gestational age
- Abnormalities in tone, such as:
  - * hypertonicity
  - * hypotonicity
  - * posturing of limbs
- Delay in achieving gross or fine motor milestones; abnormal patterns in the achievement of motor

milestones
- Abnormal neurological exam
- Unusual behaviors such as:
    * unconsolable crying
    * sleep disturbance (e.g. either too much or too little)
- Feeding difficulties

Environmental risk

Referrals to early intervention should be considered for children who are at high risk for delayed development because of limiting early environmental experiences or conditions.

Environmental risk facctors include, but are not limited to, the following:

- Family situations, such as:
    * parental age - very young mother/parents
    * parental stress (psychiatric or physical)
    * developmental disability of mother and/or father which interferes with care-giving (mental retardation and/or physical handicaps such as deafness, blindness, etc.)
    * maternal and/or paternal substance dependence
    * known history of child abuse or neglect (of the parents or of previous offspring)

(These "Criteria for Referral Definitions" were adapted from materials developed by Project WELCOME, a joint activity of Children's Hospital Medical Center and Wheelock College, Boston, Massachusetts)

SUPPLEMENTAL REPORT

EARLY INTERVENTION PROJECT

A Handicapped Children's Early Education Project
of the U. S. Department of Education

conducted under the auspices of the

Maine
Interdepartmental Coordinating Committee for Preschool Handicapped Children

in conjunction with the

Department of Mental Health and Mental Retardation
(Augusta, Maine)

and the

Early Opportunities Project
(Norway, Maine)

and the

Baby Start Project
(Machias, Maine)

EARLY OPPORTUNITIES PROJECT
(0-to-3 Assessment and Service)
November 1984 - May 1985

Norway, Maine

by

Sue-Ellen Myers, Coordinator

What Worked, What Didn't, and Why

Our high acceptance rate of participation in the project (averaging 85-90%) is a reflection of the training of and coordination with the staff of Stephens Memorial Hospital. The hospital staff were well educated by the Public Health Nurse Liason in the use of the screening tool (DPHN Form 52). Staff and nursing directors participated in the governing board activities and on the Service Assessment Team. This participation gave them a broad perspective of the project as well as input and loyalty to its goals.

Stephens Memorial Hospital is small; the Obstetrics Unit has six beds and usually only two or three are filled at one time. There are about 300 births per year at the hospital. The size of the OB Unit allows a high degree of friendliness to develop between patient and nurse. The OB nurses are in good positions to offer the Early Opportunities project's services. An example of this concern for patient and a willingness to join in the project can be illustrated with the case of a 20-year old mother giving birth to her third son (ages two, one, newborn).

> This woman and her husband were both high school graduates, and both from high risk families. She had two siblings diagnosed as having childhood schizophrenia and a mother who was an alcoholic. The husband was a cocaine user and from a family of alcoholics. The hospital nurses did not know of the drug and alcohol abuse in the baby's family, but were aware of the mental illness. The family, however, could not be persuaded to sign on to the project. One night, the evening shift OB nurse had free time and was spending it with the mother, who was due to go home the next morning. After lots of tears, the mother admitted to being afraid of her husband and his cocaine use, of hating the thought of having three boys under three years old, and of having serious financial problems.
>
> The nurse promised to contact some one who could help her with some of the difficulties. She did this and the hospital allowed this nurse to visit the mother when she went home, establishing a link from the hospital to the community. The nurse could then introduce her friend, who could help the mother with her parenting skills. That friend was the "Parent Place Coordinator," a member of the Service Assessment Team.

That child was born two-and-a-half years ago. The mother has been a participant in three multidisciplinary team meetings since

then. The road has been rocky for the family: Child Protective Service workers "opened" the family, the mother sought personal counseling, then a divorce, then marital counseling. The family was evicted from two apartments; the husband served time in jail. But, for the past nine months, both parents are together, working, and sending the children to day care. The two older boys attend a speech-and-language preschool program. The parents pay for all services and transport the children themselves. The family frequently calls Early Opportunities to inform us of changes or to seek help, such as counseling or day care information. The success of this family was certainly due to hospital intervention, and to hospital staff having the right and the time to visit with a patient who had serious reservations about her ability to parent.

Other hospital patients were not so willing to sign on to the project. Mothers might initially agree to answer questins on the "52" and to have a home visit by a Public Health Nurse, but after the husband learned of them, or once the family went home, the home visit would be cancelled. The idea of the "state nurse" visiting is seen as a stigma in some families. These families seek privacy, and fear having a stranger check their baby and advise them on feeding, bathing and parenting issues. The Yankee tradition of doing without help is strong.

> One such family gave birth to a baby at 29 weeks gestation. The baby was very sick for a long time and finally came home after three months in the hospital. The mother sought help and some one to confirm that her baby was all right. The father, however, didn't want "state help" and refused to permit services or Public Health Nurse visits. He would not even fill out a Medicaid application for the baby, although they would have been eligible. Medical staff prevailed in this case to persuade the parents to use Medicaid for such a sick baby, and to seek professional nursing advice. The family's medical office encouraged them to participate in Early Opportunities to help coordinate the services the baby might need.
>
> This encouragement was not as successful as hoped. This family still remains on the perimeter of the project; the mother has attended a Service Assessment Team meeting and expressed her desires for help and advice. But the family is very remote from services, and the father refuses participation, unless it is medically necessary.

Our high rate of participation in the project is also an indication of small town "comfortability" with the service providers. The initial Public Health Nurse assigned to our project was well-known in the area for many years, and had served two generations of the same families. People often did trust her, and would come to a Team meeting or participate in the project although they had expressed some initial reluctance. If this nurse come come to the Team meeting with the family, and act as their friend and advocate, the referral was usually successful.

One mother, who was deaf, was pregnant with her third child. Her first child is nine years old and had legally been removed from the home. The second child died in infancy. The mother was very nervous about raising the new child, and expressed concern about "the state taking it." The Public Health Nurse encouraged her to meet the Early Opportunities Service Team and, through an interpreter, talk about what she might need to successfully raise a child. The nurse realized she could not regularly visit the family unless the child were sick, and that some one was needed to visit regularly, to help this mother with parenting issues.

Through the intervention and trust of the Public Health Nurse, and through the project, a Parent Peer Aide was found who could visit the family once or twice a week, offering parenting information, demonstrating proper play with the infant, and occasionally driving th mother to shop, or to the doctor's office. A TTD was loaned to the mother so that she could telephone the doctor and friends. Devices were purchased by the project that would indicate when the phone rang, or when the baby cried. An interpreter was hired for medical visits, so that the mother could understand developmental issues. The baby is now two years old. He demonstrates some speech-and-language delays, and is attending a nursery program for that reason. The mother would like to have marital counseling, but finding an interpreter for counseling is expensive and difficult. The mother does attend parenting groups in Norway and has a long-term home visitor who demonstrates appropriate behavior management techniques and ways to play with her child.

Changing the Early Opportunities project's focus from post-natal to pre-natal, in 1986, permitted more time for the family to think about the project, meet some of the providers, and see how their own needs might be met by their participation in the project. Early Opportunities found that - although the hospital nursing staff was very well-informed and willing to talk about the project with new mothers - there was often not adequate time before discharge. Most mothers stay in the hospital only 36-48 hours, and much of that time is filled with visitors. A quiet time to explain the project and meet with parents was often difficult to find.

At the suggestion of the medical staff, it was decided to use the "Form 52" screening tool in medical offices, and to train medical personnel - especially office nurses - in its use. Information about the goals of Early Opportunities was also provided. Although it was rare for the Service Assessment Team to meet before the birth of a baby, Early Opportunities did receive many more pre-natal referrals and we began to anticipate services for them. These families had a good deal of knowledge aout the project, and its service potential, before the baby was born. Difficulties they might encounter after the birth, such as unemployment, eviction, or a sick baby could be addressed promptly by the case manager, who already knew the family.

Because of the omnipresent quality of the Service Assessment Team, the governing board - the Working Group - decided that families with only one specific service need did not need to attend or participate in a Service Assessment Team meeting. The experience of meeting eight new people and discussing one need, such as a link to low-income housing, or a parent-to-parent referral, was too stressful for most families. Our procedure changed to that of having the Case Manager present the case to the Team. Those families needing help would have their needs discussed by the Team without their attendance at the Team meeting. The Case Manager would then return to the family with Team suggestions which the family and the Case Manager could implement together.

> One 15-year old mother was very shy and would not attend a Team meeting. She did, however, attend Teen Parenting classes at the Oxford Hills High School. These classes were offered by the Parent Place Coordinator, a member of the Service Assessment Team. This woman became the Case Manager for the teen mom, and helped represent her needs to the Team. As a result, this mother was able to utilize counseling and support groups to help her with parenting, and maintain a link with the Team through her Case Manager.

The multidisciplinary Service Assessment Team became a very important part of meeting the needs of the infant who was at-risk for serious, environmentally-caused developmental delays. The environmental stresses and personal crises of many families often required a unique approach to reaching and serving them.

> One family was rurally isolated, living in a burned-out trailer shell with no running water, no electricity, and only intermittant wood stove heat. Their transportation was unreliable. Both parents were special education graduates from the high school, and could not maintain employment. Their baby was born prematurely and weighed only three pounds, though she was healthy.
>
> Because of the lack of a safe and healthy home, the Team met with the parents to discuss services this family might use to help them succeed in raising their child. The medical doctor for the mother and child was an integral part of the Team. Other members included: a Child Protective Services worker, a mental health counselor, a Child Development Worker, a Bureau of Mental Retardation adult caseworker, the Parent Place Coordinator, a Public Health Nurse, a hospital nurse, and the Early Opportunities Case Manager. The Team members were numerous, but so were the "red flags" in this family's situation.

After two years of working together, the Service Assessment Team had learned to delegate most mental health issues to the community mental health center counselor. She could raise counseling and substance abuse issues which the rest of the team could follow up on to plan adequate services. The Team has not changed its basic

membership in two-and-a-half years, so discussion can flow among members freely. The family is included in this discussion, and concern for their participation in and understanding of the Team process is vital to the Team's members.

This particular family was confronted with the most basic question - could they provide a safe and healthy home for their daughter. The Early Opportunities approach was positive - we wanted the family to stay together. However, we did want the parents to realize the importance of a safe, healthy environment. Housing options were discussed - would the family move, how would they pay a monthly rent, what type of home did they want (trailer or apartment), etc.? The family decided to live with the woman's mother until they could find a trailer rental.

The next issue discussed was the health of the baby girl. Did the mother know how to feed and care for a small newborn, dress her appropriately for the temperature, know when she was ill, etc.? The mother, who would be the primary caretaker as the father intended to find work, admitted that she needed help. Too many people were giving her advice (grandmother, aunt, brother) and she wanted <u>one</u> person to help her. However, this mother's parenting skills were so limited that the Team felt three workers were necessary to provide frequent visits. In this rural area, the possibility of one worker visiting daily for several months is not feasible.

> With visiting services arranged, the Service Team selected a Case Manager who could monitor and coordinate other services, such as Food Stamps, Women-Infants-Children (WIC) and Medicaid. This family was difficult to work with. The Service Assessment Team wanted to be a team with the parents in successfully raising this premature baby. The parents wanted some help (primarily a housing payment) but actually wanted to be left alone with their child. The baby has been home from the hospital for a month. The mother has started to avoid visitors by leaving home early in the morning; the baby has been left with relatives. The father could not find final employment and the family has no money. WIC has paid for formula for the baby, but there is no money for diapers, soap, and baby items. The baby became sick with a virus, and the mother began using the hospital's Emergency Room to avoid her own doctor; she didn't want him to know how dirty and sick the baby was.

This case study is rather grim, but illustrative of the over-whelming environmental problems our families and the Service Assessment Team often face. Should the baby be placed in foster care? Are the parents mentally capable of becoming responsible parents? When should the Team refer the case on to another agency and close the case? Today, this family is still together, but tomorrow Child Protective Services may need to intervene, and remove the child. This family's early referral to the Early Opportunities

Project may have prevented a disastrous end for this baby, even if the child is eventually removed from the family.

The Service Assessment Team identifies and coordinates services for its clients well. Success of the Team approach to problems seems to be centered on the size of the Team as viewed by the client. Eight professionals, most of whom are strangers to the parents, are frightening. Addition of the case management technique has lessened this problem.

Another issue faced by the Team is its approach to serious environmental risks faced by an infant. How strong should the advocacy for the child be? Should the Team work to place children in foster care, or should the team not see families who exhibit too many serious risks? We accept client referrals as appropriate because we feel all services available in the Norway area are represented on the Service Assessment Team. A collaborative effort at one time is better than constant linear referrals from one agency to another!

> The case of a single mother who has schizophrenia (controlled with medication) and is raising three children can illustrate this point. Having all service providers - mental health, child protective, the pediatrician, the Parent Peer Aide - sit together with the mother to plan a service plan allowed every one to hear the same issues and concerns. Certainly this was not a one-service family, and many agencies needed to plan together for the success of this family.
>
> A year-and-a-half later, the family is functioning smoothly. The mother has made friends through the Parent Place - friends who helped her get a driver's license and who swap babysitting chores. These friends give this mother the self-esteem and confidence to continue her life as a single mother to three preschoolers.

Statistical Summary
January 1,1986 - March 31, 1987

A.	Total Births at Stephens Memorial Hospital			378
	Model	351	(92%)	
	Non-model (Non-catchment area)	27	(8%)	
B.	Total Screened at Stephens Memorial Hospital			336
	Without report (Parent declined the screening)	55	(16%)	
	With report	281	(84%)	

Hence, 84% of screenings at the hospital were "with report" and 74% of all SMH births received a "screening with report."

C.	Risks Identified (from "Screened with report")			281
	None	139	(49%)	
	Established	1	)	
	Biological	14	)	
	Environmental (61%)	87	)	
	Established/Biological	2	)--142	(51%)
	Established/Environmental	9	)	
	Biological/Environmental (19%)	27	)	
	All 3	2	)	

Hence, 51% of SMH hospital "screenings with report" indicated risk factors of some kind. Of those hospital screenings that did indicate risks (142), 61% were Environmental, 19% Biological/Environmental, and 20% were "all other" categories.

D. Completed Home Visits (There were 304 referrals for home visits by Public Health Nurses. Of these, the following are the status statistics at the time this report was compiled.)

Unable to complete	79	(25%)
Completed	210	(69%)
Incomplete	15	(4%)

E.	Risks Identified by Home Visits			
	None	97	(46%)	
	Established	1	)	
	Biological	9	)	
	Environmental (69%)	78	)	
	Established/Biological	3	)--113	(54%)
	Established/Environmental	5	)	
	Biological/Environmental (15%)	17	)	
	All 3	0	)	

Hence, 54% of Home Visit screenings indicated risk factors of some kind. Of these Home Visit screenings that did indicate risks (113), 69%

were Environmental, 15% were Biological/Environmental, and 16% were "all other" categories.

To summarzie, over a 15-month period, 51% of all "screenings with reports" at Stephens Memorial Hospital indicated risk factors; 54% of Home Visit screenings indicated risk factors. The predominant risk factors in both cases were Environmental first, followed by Biological/Environmental.

F. Disposition of Cases (Clients with identified risk factors following the Home Vist were 113. Disposition of these 113 were as follows.)

Team referral made		30 (26%)
Team referral not made		83 (74%)
PHN to continue visits	20 (24%)	
Anonymous Team discussion	6 (7%)	
No intervention: Monitor	52 (62%)	
No intervention: Closed	5 (6%)	

Hence, over 15 months, 26% of the clients with risk factors after the Home Vist were referred to Team. This statistic is deceptive, because it reflects only the clients referred to Team in a given month, following a birth during that month. This number does not indicate clients referred to Team whose children were born two or more months prior to referral. The number of actual referrals to the Early Opportunities Team is higher than 30. A more accurate statistic for this period of time is the number of active clients on the project's caseload. At any given time over the 15 month period of this report, the caseload averaged between 35 and 65.

Baby Start Project
(0-to-3 Asessment and Service)
1984 - 1987
Machias, Maine

by

Ann F. Pike, R.N.
Assessment Coordinator

I. ISSUES RELATIVE TO INFORMATION/ACCEPTANCE/COMMUNICATION

A. With hospital personnel

Representatives of the state level committee looking at 0-to-3 programming approached the Down East Community Hospital to create interest and enlist support for the project. Initially, the hospital representatives were interested and willing to explore the parameters and impact of having such a project. Thus, the "informing" was quite successful at achieving the desired "outcome" which was "interest."

Unfortunately, an apparent lapse of communication occurred between this informing stage and implementation of the model. The hospital representatives, for a number of reasons, did not become involved in the discussion and planning, and therefore did not feel that the project belonged to them. Efforts at repairing this relationship were successful, but time-consuming. The experience taught that the hospital must be a key member of the planning and implementation team for the model to be embraced. The unintended message that the hospital was somehow less important as a member of the team was transmitted down to the staff, who held a certain resistance to participation for some time afterwards.

Other issues relevant to hospital acceptance and participation are: who will complete the screenings and what the hospital will feel it gets in return for the effort it puts in. These are tied together.

Initially, in Machias, the Assessment Coordinator went into the hospital and largely did the screenings. This had several detrimental consequences: the screenings were based on a single observation by the assessor and her ability to effectively elicit information; the OB staff may have received the unintended message that they were not competent screeners; valuable information collected by the OB staff may not have been transmitted to the assessor; and finally, families were "missed" if the assessor was away for a number of days.

Coincidentally, this process was turned around when a turnover in project staff occurred and there was not an assessor for a period of several weeks. The hospital staff picked up the screening function and the new Assessment Coordinator promoted their role as the best and most appropriate screeners of their patients. The initial effect was a small drop in the number of patients accepting the screening. This

may have been due to variable presentations; a single screener repeatedly informing parents and obtaining consents would undoubtedly perfect a successful approach.

However, in order to avoid "misses" it was believed that all staff should have the ability to inform and screen. The coordinator's efforts were, therefore, spent at developing a presentation to parents that could be uniformly used by staff, assisting staff in implementing a plan and tracking system to ensure 100% screening, and increasing staff skills in making observations, interviewing and the documentation of risk factors.

Staff also need to have education on Environmental risks and early intervention, in order to believe in the value of their efforts. A feedback system was also devised so that staff could learn about outcomes for the families they had screened. Another method of increasing participation of hospital staff is the opportunity to observe home visits with community health nurses. The acceptance rate of families for screenings rising from 60% in November, 1985 to 80% in February, 1987 bears out the increasing acceptance.

B. <u>With service providers</u>

The discipline serving the largest number of the 0-to-3 population are the community health nurses. Critical to their acceptance is involvement in the planning stages right on through the implementation of the model. They need to have a strong voice in design and service delivery, as they have the greatest contact with the service population and can usually enlist client acceptance.

By and large, the Machias project was successful in enlisting this discipline's participation. The supervisors in both of the nursing agencies (i.e. State and contracted) were integral in planning and supportive in model implementation. When the staff nurses saw return for their efforts, by way of increased services for their families and professional support for themselves, turf issues were resolved and "buy-in" was achieved.

Physician participation has been varied to extremes. The level of participation seems to be related to when they became informed about the project: those physicians engaged later in the process - when the project was more together - seemed to participate more readily. Again, those seeing tangible benefits for their families were the ones who referred repeatedly.

There was also a correlation between participation and prior positive experiences with early intervention projects elsewhere. Most physicians receive very little training with other disciplines, in a multidisciplinary manner. A process of subtle re-education needs to occur, whereby the physician learns what he may gain for his patients and himself in exchange for involvement. The change noted

over time in Machias is that physicians who previously did not acknowledge receiving information regarding their patients, or who did not acknowledge receiving notifications of meetings, are increasingly calling in with information or concerns prior to meetings.

In addition, these semi-participatory physicians are more accessible to the coordinators for problem-solving and planning outside of the meetings. They have been cooperative in implementing suggestions into their medical plans of care.

> For instance, Dr. B., in response to a notice that his patient, Mrs. D., would be reviewed at a team meeting, called the coordinator to report that Mrs. D. had an acute depressive reaction. He had prescribed short-term therapy of anti-depressants and regular counseling. He urged Mrs. D. to seek counseling at either of two local agencies, or return to him. He was concerned that he had not heard from her since her crisis, and he wanted the team to incorporate these concerns in their plan. The team used the information to encourage counseling and assist Mrs. D. to access this service. The doctor received the report of the team meeting and the Service Plan that included his report and recommendations. Subsequently, Dr. B. has shown an interest in other activities of the project, and encourages his OB patients to participate in the screenings.

Our Machias site has two service teams. The second team was based in Calais, a central service and client population area. The Calais team has shown the highest level of physician participation. Key to the team is the local pediatrician, who was engaged by the project when she opened her practice. Thus, her newness to the geographic area, as well as her lack of knowledge of service resources, was instrumental in her active participation in the early intervention model. She is the highest referring source to the program. Dr. A. is the only pediatrician serving her population center, and her enthusiasm has had a "trickle" effect on other physicians, making the medical component in Calais very strong.

Training and development of the earlier, Machias team was a lengthier process than in the Calais area, reflecting the developmental process of the whole model. Key issues in establishing the initial Service Assessment Team were time commitment, training in discipline knowledge, jargon and the development of clear roles. Agency support proved to be an essential factor for team members' participation. Turf issues arose periodically over the two year development period, although these varied by discipline. Commitment of core team, in terms of meeting attendance and outside work, also fluctuates. The Machias team has held occasion "retreats" to work out system issues and reaffirm commitment. The experiences of the Machias team have all benefited the Calais team, which was trained in a shorter period of time.

A change over time has been seen in the mental health component of the team. As the other disciplines look to these professionals for approaches and information for handling family systems problems, the therapists/counselors have become engaged in sharing their knowledge and skills. Colleagues are able to improve their skills through this transdisciplinary sharing. This has, in turn, increased referrals for mental health services by professionals not previously referring.

A by-product of the team's increasing knowledge base and awareness is that the team seeks to broaden its depth and scope through the addition of other specialists (substance abuse counselors/family abuse counselors/financial resource personnel) to the team. What was once believed to be a relatively closed system of disciplines needed to serve families has become more open and adaptive to serve multi-level needs of families. Team members learn to appreciate the unique skills that each member contributes and this multi-faceted contribution is conveyed to the families.

In general, service providers need to feel that they will gain, rather than lose, by participation in a multi-disciplinary team model of service coordination. They need to feel that their relationship with their client will be supported and enhanced by their efforts. This is accomplished through supportive collaboration, on-going communication as to status, change among providers and clarity as to each provider's role and responsibilities in working with the family. No provider's role can be minimized in this effort, because that individual will channel his energy elsewhere. Providers need feedback that demonstrates that their work has been valuable.

c. <u>With parents</u>

The informing process with parents has changed repeatedly. Initially, the maternity patient was asked if she would consent to participation in a pilot program, and have a home visit. Depending upon the finesse of the informer (usually the screener) this approach had varying degrees of success. Underlying issues around informing needed to be worked on.

Prior to the model design, high risk infants (usually designated as such due to biological and/or established risk) around the State of Maine were referred to Public Health Nursing. A high risk report was sent regardless of parental consent. Would the new system of offering screening to <u>all</u> new mothers supplant or supplement this system? What would happen if a biologically high risk infant's parents declined screening? Finally, how would families who already had community nursing services in place be informed and screened? Procedures were not formulated to address these issues prior to implementation of the model, and had to be negotiated as they arose. What we have learned is that a uniform policy and procedure that can

be used regardless of specific circumstances serves to eliminate confusion.

Other issues involved in informing parents of screening and assessment was the confusion that arOse when the informing included a description of the service component of the project. Since a family is only referred to the team if risks or needs are identified after a home visit, and with consent obtained at that time, it was learned that the assessment and service components should be dealt with as separate entities.

New leaflets describing only the nursing assessment and the home visit were designed as an informing tool. This leaflet has been well received by patients and OB staff alike. Since its implementation in January, 1987, the acceptance rate for screening has increased from 61% to 85%. Another change, over time, is that which occurs by word of mouth: a mother who enjoyed the nursing visits tells her pregnant friend of the service.

Informing patients regarding the role and function of the service team in coordination and service provision is done by the service provider. The project's role in this informing is to ensure that providers have substantive knowledge regarding what the team can offer, how the meeting is conducted, what the process is for service delivery, and what benefits the family might hope to gain. In addition, the project must strive to reduce or alleviate factors which would be stressful to the family, if it participates in the team meeting. Our team has spent numerous training sessions to increase our skills at making parents feel comfortable and important in the team process. Our informing consent reinforces the important role of the parent(s) as the primary decision-maker, and emphasizes that services are only implemented with parental consent at each step of the process.

This informing and continued reinforcement leads to acceptance and participation by the family, in actual practice. They learn, through experience, that the team is a vehicle to help <u>them</u> plan and coordinate services and that <u>they</u> will control the extent to which they will use it. During the first year, families did not come to team meetings and there were few referrals. Presently, half of all families served participate in the team meeting and referrals average 10 per month.

> An example of this process can be demonstrated in the case of Candy K, a multi-handicapped three moonth old, recently adopted by a high-functioning married couple. She was referred to the project by the adoption agency; a referral for assessment and informing was made to the Public Health Nurse. The family consented to team participation and - following a neuro-developmental evaluation - an intake meeting was held.

Mrs. K. arrived with Candy and was introduced to team members and the meeting format. Mrs. K. was encouraged to discuss Candy's special needs and the impact that Candy had made in her family's life. She was asked to discuss what her immediate goals for both Candy and the family were and what services were needed to reach them. The team verbalized to Mrs. K. the strengths they could identify in Candy and the family and reinforced her competency in caring for the family. Together, Mrs. K. and the team were able to outline a plan to meet needs and designate who would be responsible for completing each step.

After the meeting, Mrs. K. told the nurse that she felt comfortable with the team and felt positive about achieving her goals. Subsequently, Mrs. K. has attended all follow-up meetings and contacted providers when the plan needs revision. She has accepted this model readily because she felt her primary role was acknowledged, respected and supported.

II. ISSUES RELATED TO THE PRIMARY MODEL DESIGN

A. In-hospital screening

Probably the most basic element of the model which has changed over time is the evolution in thinking regarding screening/referral. Initially proposed as a "new" model, screening was approached as something "different." In reality, screening has been an on-going process in nursing practice, particularly in regard to the birthing family. It has been standard practice for quite some time for the nurse to observe for risks affecting the mother/infant bonding process, and the support system in which this dyad will exist. OB nurses have long known that - as a part of nursing practice - they can intervene in ways that will enhance positive factors in the perinatal period, and turn around negative factors.

The recognition of the nurses' practice must be incorporated into the design; i.e. the nurse's assessment and intervention skills need to be enhanced and built on. In addition, the hospital staff needs to be educated on community nursing practice and the continuum of care that exists when referrals are made. Thus, the design will build on skills and resources that already exist. The role of the project decreases once these networks and systems are highlighted and strengened. The Assessment Coordinator's role has changed from initially modeling the screening, encouraging referrals, educating on impoving observations, interviews and documentation to that of serving as a reinforcer, linkage agent and consultant.

A related issue in model design is the choice of the screening tool. The initial tool, that looked for deficits in the family, was overwhelmingly rejected by staff as well as families. Conversely, a tool that brings out strengths creates a positive approach to assessment.

B. Home visit assessments

As consents increased in the hospital, the nurses in the field felt the increase in referrals for their services. It was erroneous to assume that families would be visited once, and discharged. The majority of families desired on-going nursing visits for parenting education and support. Caseloads increased. It is important that community nursing agencies recognize that - if the program is well received - referrals will increase significantly.

Plans must be made to accomodate this increase and prioritize who will be served. Families need to know that the service will be directed at increasing knowledge, skills and adequacy to access servces needed to meet their needs independently. The project should direct its efforts, also, at streamlining paperwork that it requests from the nurses and other providers participating in the model. Requirements/procedures should not additionally burden providers or impede access to services.

C. Referral to the Service Team

When the Baby Start Project began, the service team heard the results of all home assessments anonymously. This was to serve two purposes: 1) to "train" the team on family issues, 2) to "train" providers on how the team might help. Problems related to this "anonymous review process" involved confidentiality and consent issues, as well as the providers (composed primarily of nurses) feeling interrogated and judged. Although discussions occurred frequently over these issues, resolution only came over time as direct referrals to the team increased, and as hospital issues sorted themselves out. Specifically, the team became completely "booked" hearing "open" cases. The team also acknowledged its impotency in helping families/providers who aren't actively engaged in the project.

Once the philosophy that participation should be an active, forthright process for families and providers was adopted, a referral procedure was developed. This procedure spelled out the informing and consent process and specific roles of family, provider and team. These changes, that occurred over time, resulted in providers and families being less confused over what to expect as a result of their involvement in the team process.

As a result, many families consent to participate when a provider recommends it. All Baby Start services are coordinated through the team. Although there are probably a few situations that could be handled by the Coordinator alone, the consistent and uniform method of coordination seems to increase trust in the model.

III. ISSUES RELATED TO THE SERVICE TEAM PROCESS

A. As it affected service planning

There is little question as to whether two (or more) heads are better than one when it comes to service planning. Our team found that both the families and providers gained from a multidisicplinary approach. Service recommendations take into account a larger view of the family system, and what can be achieved.

Changing from unilateral to group decision-making was slow. Initially, the nurses made presentations of absent families that contained a variety of information and a specific request for service(s). The request was represented as a family's choice, and endorsed by the nurse. Frequently the nurse would be in the position of defending or advocating this choice. The team members sometimes felt that they should support this request or risk alienating both the family and the nurse.

> A case that follwed this description was that of 3-month old Sally. In September, 1986 the nurse described the reason for referral in the problem statement as "holding head to right - sleeps in stroller - no crib - no money for crib." Since the family did not attend the meeting, and there was no additional information, the team decided to supply a crib and refer for neuro-motor screening. No one had a real sense of how the family was functioning or what impact our recommendation would have.

As the team gained a stronger sense of purpose in looking at family systems, the flavor of the meetings changed. A case that was reviewed during this period had the earmarkings of following the pattern described above.

> The mother had been referred during her pregnancy for respite. She had an active two-year old from a previous marriage, and there was marital and financial stress in her present family. Mrs. B. did not attend the meeting, and - based on the nurse's recommendation - respite was provided.
>
> Subsequent to delivery, the family situation deteriorated. Mr. B. was jailed for theft; Mrs. B, and the children were sharing a substandard home with friends. Two-year old Mark was completely out of control, and the infant - Mary - was often neglected. By this time, Child Protective Services were involved. The team referred Mark for developmental evaluation, to get a sense of where he was in terms of needs. Mrs. B. was inconsistent about keeping home visit appointments; she was frequently moving about and substance abuse was suspected. The only service she consistently utilized was respite daycare for Mark. However, it was learned that she utilized some of her respite time to babysit other children;

Mary did not seem to be getting the individual attention that the respite was to have allowed.

In late fall, 1986, when Mrs. B., through the nurse, asked the team to provide a bed for Mark, the nurse recommended a home counseling service for Mrs. B., that she had not requested. The team believed the recommendations were missing the point. The discussion that ensued raised the issue of providing services that the client had not requested. A second issue was that of enabling the client to ignore her real problem, which was likely the substance abuse.

The team's recommendation at the end of this contraversial meeting was to have the nurse and the CPS worker jointly meet with Mrs. B. to assess her goals and assist her with prioritizing a plan. Unfortunately, Mrs. B. moved out of the county before this meeting occurred. We later learned that the children were removed from her custody, and placed in foster care.

The team felt it had come to a productive place in its final approach, albeit by trial and error. We hadn't gathered enough information nor done a comprehensive assessment in our prior recommendation.

A third case gives credence to the evolution of team competency.

Eleven-month old David was referred to the team in January, 1987 by an interim community health nurse. David had an extensive history of recurrent respiratory infections requiring hospitalization, complicated by living in over-crowded, smoked filled housing. The nurse, having consulted the physician, was recommending that the team authorize purchase of an air purifier for the home. Neither the nurse nor the family attended the team meeting.

Issues raised by the team included: the need for the family to acknowledge and modify its behavior in relation to David's health; would the purifier enable the family to ignore its responsibility for David's environment; would the purifier achieve the desired outcome? The team decided to refer these questions back to the family, nurse and physician. The physician responded positively the concerns, and reinforced to the family the need to keep the home as smoke free as possible for David's benefit.

Six weeks later, the case was heard again. The family had made changes in their smoking behavior and the physician felt that a purifier might now be appropriate. The team and family shared the rental cost for a month; based on David's improvement, the unit was later purchased.

Another case illustrating the team's approach at focusing on family goals, rather than provider goals, was that of Jamie G.

Jamie's mother, Betty was a single eighteen-year old high school dropout, living in an overcrowded home with her retarded

mother and brother. Her abusive boy-friend had abandoned her when she became pregnant with Jamie. Although the referring nurse and team recognized that Betty and Jamie could benefit from multiple services, Betty was clear that the only assistance she wanted was help in locating different housing. Once this was accomplished by Betty herself, the team was faced with deciding whether to monitor or close the case.

The team felt that Betty's competence and independence would be fostered by clearly communicating our recognition of her strengths, giving her information on resources and how to access the team in the future; then closing her case. Acknowledging Betty's responsibility clearly empowered Betty to refer herself to the team four months later, for additional needs.

These cases demonstrated the change, over time, in the team's view of its role and its family-centered approach to service planning.

B. <u>As it affected the identification of and/or development of resources</u>

Multiple disciplines representing a variety of agencies, geographical settings and personal experiences can offer a broader and more creative use of resources.

In the case of Billy T., the team was able to identify several resources unknown to the family case manager. The T.'s subsisted in a 2-room shack without water or adequate heat. Billy and his brother appeared to be environmentally delayed; Mrs. T. seemed chronically depressed and Mr. T. was abusive. The family needed assistance with a number of problems. The Child Protective Services and Child Development workers were able to assist and advocate successfully for a wood stove for the family. The Homemaker on the team knew of a ceramic class where Mrs. T. could gain some positive feelings about herself by attending, and a social worker on the team knew of a resource to obtain used furniture. Finally, the nurse - in conjunction with other team members - was able to identify daycare and transportation services for both children.

By virtue of its direct service budget, the team was able, in many cases, to access services faster than through traditional means.

Crystal A. was in need of a corner chair as part of her therapy for dislocated hips, arthrogryposis and profound gross and fine motor delays. Crystal had Medicaid from Texas; her parents had private insurance and had an application pending for Handicapped Children's Program assistance. It was clear that the corner chair would most certainly be covered by one of these three avenues. However, the sort process might take weeks. The team was able to expedite her access to the chair by guaranteeing payment to the

vendor and assisting the family with submitting the paperwork to the correct agencies.

By having numerous agencies represented on the team, efforts at filling resource gaps became a unified and unifying mission. An example of this collective advocacy took place when the team identified the need for systematic parenting education. Once a curriculum was selected and an instructor identified, team members generated interest within their agencies and among colleagues. Potential funding sources were identified. The first class began 3 months later under a joint funding package, with a third agency planning to pick up the program for its next cycle.

Another group effort was aimed at drawing attention to the need for low income family housing. Currently the issue has generated enough interest to stimulate the formation of an ad hoc committee to study county needs. Team members have learned that when they share problems and information, limited resources can be creatively shared to maximize their impact.

C. As it affected the actual delivery of services to families

A valuable insight gained by the team was the wisdom to time services appropriately to the needs and readiness of the family.

> Given the fact that twelve-month old Peter J. was developmentally delayed in all areas by 8-10 months - the only child of well-educated, middle class parents - it was easy to recommend service plans that included further evaluation, occupational/physical/communication therapy, parent-to-parent networking, infant stimulation and daycare.
>
> When Mrs. J. failed to meet the peer parent, unenthusiastically kept therapy appointments, and declined inclusion in a mother's group, it became obvious that our timing was seriously off. Mr. and Mrs. J. were dealing with a great deal of shock, anger and denial at learning that their long-planned for son was severely impaired. We had failed to assess the family's needs and plan services that would accomodate them at their own pace. Once the timing was turned over to Mr. and Mrs. J., they were able to embrace the plan as their own.

This lesson having been assimilated, initial recommendations for Carol D. were very different.

> Carol was identified as profoundly mentally impaired within weeks of her birth. Her single mother lived an alternative lifestyle with Carol's father in an isolated area, and drug useage was suspected in the etiology of Carol's problems. Although the team knew, professionally, that Carol and her family would require a wide variety of services to achieve optimal outcomes, only minimal services (nursing and physical therapy) were recommended initially.

Since Mrs. D. did not attend the meeting, it was noted that further assessment was needed prior to comprehensive planning.

A slightly different change, over time, involved the use of multiple providers working with a single family. It was learned that many families simply cannot cope with numerous services delivered simultaneously. For the L. family, whose chief problem was marital stress and parenting dysfunction, visits from the nurse, Homemaker and Home Advisor seemed to exacerbate the issues. Although the providers communicated well with each other and were consistent with the family, the team found it necessary to request that one of the providers pull out. Efforts were made at providing transdisciplinary training to those still working with the family, to fill in some of the skills that the absent provider had possessed.

This transdisciplinary approach was also used with the G. family, who were highly suspicious of social service providers to begin with. Both Mr. and Mrs. G. are mentally retarded and their son has received preventive services since birth. When the family felt the nurse was becoming intrusive, the child development worker was given specific parenting and safety issues to assess until a different nurse could be introduced into the home.

The quality of service delivery is improved by the team process. Not only are case plans made jointly by family and providers, and thus more consistently followed, but providers feel there is greater shared accountability for delivering what is agreed to. Further, providers are able to return to team for problem-solving and support when progress toward goals is not evident. The process of training and building a team for service planning and coordination is slow and costly. However, the pay-off in long term cost savings is evident with respect to unduplicated efforts, pooled energies and increased resource development. Washington County service providers are committed to this model, and plan to extend it to the entire 0-to-5 population.

Baby Start

100 Court Street, P. O. Box 277
Machias, Maine 04654-0277
1-800-432-7846 255-8641

May 26, 1987

RECEIVED
DEPT. MENTAL HEALTH &
MENTAL RETARDATION
JUN 1 1987
AM 7 8 9 10 11 12 1 2 3 4 5 6 PM

DOWN EAST COMMUNITY HOSPITAL

Total births 1/86 - 4/87 -	210	
non-Model (Canadian; Stillbirth)	7	
Total Model	203	
Screened with report	136	67%
Screened without report (declined)	66	32½%
Missed	1	0.½%

Other information regarding risks, home visits and disposition is found on enclosed statistical report.

YEAR-END REPORT
(1986)

I. HOSPITAL BIRTH DATA

A.	Total births			170
	1. Non-model births	5	(3%)	
	2. Model births	165	(97%)	

II. HOSPITAL SCREENING DATA

A.	Screening without Report			54 (32%)
	1. Declined	51		
	2. Left without signing	0		
	3. Other	3		
B.	Screening with Report			113 (68%)
C.	Risk Identification from Report			
	1. None	29	(26%)	
	2. Established only	0	)	
	3. Biological only	5	)	
	4. Environmental only	46	)	
	5. Established/Biological	0	)--(74%)	
	6. Established/Environmental	4	)	
	7. Biological/Environmental	28	)	
	8. All three	1	)	

III. PHN HOME VISIT STATUS

A.	Referred for Home Visit			116
B.	Status of Home Visit			
	1. Unable to complete	4		
	2. Completed	108		
	3. Incomplete	4		
C.	Risk identification from Home Visit			
	1. None	53	(49%)	
	2. Established only	0	)	
	3. Biological only	4	)	
	4. Environmental only	45	)	
	5. Established/Biological	0	)--(51%)	
	6. Established/Environmental	1	)	
	7. Biological/Environmental	4	)	
	8. All three	1	)	